# Transgender Health Access in Virginia: Focus Group Report

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## Virginia Transgender Health Initiative Study Phase I

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### **Executive Summary**

In 2002, the Virginia HIV Community Planning Committee (VHCPC) chose transgender people as its next priority subpopulation for HIV prevention research. At that time, transgender people were one of four subpopulations with virtually no data to inform the VHCPC's process. The Virginia Transgender Health Initiative Study (THIS) was implemented by the Virginia Department of Health (VDH) to address this knowledge gap. In this report, we provide results from Phase One of THIS: seven focus groups composed of diverse transgender subgroups conducted in March and April, 2004. The study was designed and conducted by the VHCPC's research partner, the Survey and Evaluation Research Laboratory (SERL) at Virginia Commonwealth University. The purposes of the study were to assess the risk factors driving HIV infection among transgender people in Virginia, and their experiences in accessing medical care. Analysis of the data will assist VDH and the VHCPC with program development and resource allocation decisions.

Although the participants demonstrated a high level of knowledge about HIV, many of the participants had engaged in unprotected sex. Transgender women had unprotected sex with non-transgender men, and FTMs had unprotected sex with non-transgender men, non-transgender women and other FTMs. Other risk factors included substance abuse and unprotected sex in prostitution due to extreme financial need. Sex worker participants were mostly transgender women, but there were also some FTMs. Economic vulnerability was the primary reason for doing sex work.

Perception of HIV risk greatly varied and was highest among African-American transgender women, who also had the highest frequency of condom use. Latina transgender women used condoms less frequently than other participants. Reasons for not using condoms or other barriers included monogamy, denial of risk, substance abuse, and cultural and societal factors. IDU needle sharing occurred among transgender women who were sex workers.

Barriers to getting tested for HIV included not knowing where to get tested, fear of hostile or insensitive HIV Counseling, Testing and Referral (CTR) personnel, and fear of testing positive and its consequences. The most common barrier to getting tested was a lack of trust in HIV testing sites to keep test results confidential, especially for participants in rural areas.

High levels of substance abuse were reported by participants, with alcohol and marijuana use most common. Most participants cited their need to cope with many interrelated life stressors

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<sup>&</sup>lt;sup>1</sup> Many of the FTM (Female-To-Male) participants were ambivalent about or resented being perceived as non-transgender men, probably due to sexism. Accordingly, FTMs will be used in this report, except where participants used transgender man to identify themselves. Transgender women refers to Male-To-Female transgender persons. Where it is used, Transsexual usually implies having obtained or desiring surgical sex reassignment. See the Glossary for a complete explanation of all transgender terminology used in this report.

produced by their extreme social marginalization. Other reasons included coping with depression, coping with internalized transphobia (often as a substitute for psychotherapy) and coping with the pressures of sex work.

Some participants reported how transitioning to their chosen genders eased their depression and reduced their substance abuse. The most significant means of improving self-esteem was passing in their chosen genders, especially for the transgender women. Passing allowed them to avoid social stigma, affording them social acceptance. Passing was also important for the self-esteem of the FTMs, although some were ambivalent about being perceived as men. Gender identity affirmation through sex with non-transgender persons was another means of improving self-esteem, especially for African-American and Latina transgender women. Access to transgender care services – principally hormone therapy – was a priority need for most of the participants, since it allowed them to pass in their chosen genders. However, many participants experienced barriers to access, including lack of insurance (related to lack of employment or doing sex work as an alternative to regular employment); failure of insurance to cover their transgender care; identity documentation issues; and the lack of willing providers. Due to these barriers, many participants engaged in self-medication of hormones and injection silicone use, which involve their own health risks. Sharing of needles to inject hormones and silicone was not mentioned by the participants, although it may have occurred.

Many participants experienced barriers to access to regular medical care due to hostility and insensitivity of medical providers. Negative experiences with care providers (especially with female-to-male participants accessing gynecological care) resulted in nondisclosure of transgender status or avoidance of necessary medical care. Lack of insurance and identity documentation problems were also barriers to access. Some participants also experienced poor care relationships with mental health care providers who lacked clinical experience with transgender people or believed that transgenderism is a mental illness. Participants who did not access mental health care had negative attitudes towards it due to traditional mental illness stigma and feelings that being transgender was not a mental illness. Those seeking psychotherapy had great difficulties finding mental health providers who were compassionate, experienced, and competent.

Many participants had experienced employment discrimination and difficulties in employment, including job loss and failures to be hired. An inability to pass in one's chosen gender was often linked to job discrimination and difficulties with co-workers. Hostile work environments, with harassment and occasional physical abuse, were also reported. Generally, white collar workers, with employment longevity experienced the least discrimination. Housing discrimination was experienced by fewer participants than employment discrimination. Common housing barriers included unemployment, low

wages and the stigma associated with being transgender. Some African-American and Latina transgender women mentioned discrimination in public housing and shelters.

Many participants were survivors of violence, especially African-American transgender women, with murders of peers often reported. Many participants experienced harassment and intimidation in their own neighborhoods. Some complained about secondary victimization by the police when they reported the violence.

Unmet prevention needs reported by participants included HIV educational workshops, condom distribution, HIV counseling and testing, and individual and group level interventions. Groups with the most unmet needs for prevention were Latina transgender women, FTMs and transgender youth. Participants also mentioned cultural competency training for doctors, social workers, and other HIV workers, as well as additional training for medical providers in delivering transgender care. Other needs included financial assistance to pay for HIV treatment and job training.

Study results support the following recommendations for consideration by VDH and the VHCPC.

- Cultural competency training for medical, social service, shelter and transitional housing staffs.
- Medical service delivery training for medical providers in transgender care services and mental health service delivery training for mental health providers.
- Local clinical transgender care programs operating on a harm reduction model.
- A vocational rehabilitation program for transgender sex workers.
- Expansion of outreach and condom distribution to transgender subpopulations, especially Latina, transgender youth, and FTM groups.
- Development of transgender-specific HIV/AIDS prevention materials and implementation of transgender-specific prevention workshops.
- Improvement of HIV testing for transgender people.
- Educational programs for transgender people about transgender care.

### Introduction

Subsequent to its studies of other at-risk subpopulations, the Virginia HIV Community Planning Committee (VHCPC) chose transgender people as its next priority subpopulation for research in 2002. At that time, virtually no data were available on transgender health concerns that could adequately inform the VHCPC's process. Transgender people are those who cannot or choose not to conform to societal gender norms based upon their physical or birth sex. Transgender women are natal males with female identification or expression (male-to-females, or MTFs) and transgender men are natal females with male identification or expression (female-to-males, or FTMs). Transgender includes a variety of subpopulations, with many individual identity self-descriptors that can be hard to define. Transsexual people are generally transgender people who seek or who have undergone surgical sex reassignment. The Centers for Disease Control and Prevention currently classifies transgender people as a "Special Population" within the Men who have Sex with Men category, without regard to their gender vector. As of this date, the CDC has not yet conducted separate surveillance assessing the prevalence or incidence of HIV among transgender persons. However, there is sufficient data from studies conducted by other public health organizations suggesting that transgender people are at high risk for HIV infection.

### Literature Review

HIV prevalence among transgender women has been found to be extraordinarily high, ranging from 14% in San Juan, PR (Rodríquez-Madera, & Toro-Alfonso, 2000); 19% in Philadelphia, PA (Kenagy, 2002); 21% in Chicago, IL (Kenagy & Bostwick, 2001); 22% in Los Angeles, CA (Simon, Reback, & Bemis, 2000); 22% in New York, NY (McGowan, 1999); 32% in Washington, DC (Xavier, Bobbin, Singer & Budd, in press, 2005) and 35% in San Francisco, CA (Clements-Nolle, Marx, Guzman, & Katz, 2001). Transgender women sex workers are at particularly high risk, since they are often financially induced to engage in barrier-free sex (Boles & Elifson, 1994; McGowan, 1999; Nemoto, Operario, Keatley, Han, & Soma, 2004). A 1993 study of transgender women sex workers in Atlanta, GA found HIV prevalence to be 68% (Elifson, Boles, Posey, Sweat, Darrow & Elsea, 1993).

High rates of substance abuse have been found by all of the studies cited above, including injection drug use involving needle sharing among transgender women and transgender men (Clements, Katz, & Marx, 1999). Other overlooked means of viral transmission are sharing of needles for the injection of hormones and the injection of silicone or other heavy liquids by transgender women or illicit providers to alter their body shapes. Among transgender women, injection silicone use has been found to range from 25% to 33% (Xavier et al, 2005; McGowan, 1999; Kenagy & Bostwick, 2001; Kenagy, 2002; and Reback, Simon, Bemis, & Gatson, 2001). Although significantly under-examined, HIV

prevalence among FTMs was found to be 3% in Washington, DC (Xavier et al, 2005) and 2% in San Francisco, CA (Clements-Nolle et al, 2001).

In addition to quantitative research, a number of qualitative studies have examined the health care and social service needs of transgender people, in addition to their HIV, other STD and substance abuse risks (Boles & Elifson, 1994; Bockting, Robinson, & Rosser, 1998; Kammerer, Mason, Connors, and Durkee, 1999; Clements, Wilkinson, Kitano, Marx, 1999; JSI Research and Training Institute and GLBT Health Access Project, 2000; and Nemoto, Operario, Keatley, & Villegas, 2004). Taken together, these quantitative and qualitative studies suggest that due to pervasive stigmatization, transgender people are extremely socially marginalized and deal with discrimination, violence, and multiple barriers to access to health care and social services. In addition, they are underserved not only with regards to HIV prevention and treatment services, but also with access to regular medical care and to transgender-related health care.

### The Virginia Transgender Health Initiative Study

The Virginia Transgender Health Initiative Study (THIS) is a multi-phase, multi-year project implemented by the Survey and Evaluation Research Laboratory, under the direction of the VHCPC and the Virginia Department of Health. Using both qualitative and quantitative research methods, THIS seeks to improve health care access and identify possible means to reduce risk behaviors in its target population. The principal components of THIS include provider education; a qualitative study phase (focus groups); a quantitative study phase (survey instrument); the development of a resource manual for use by transgender people and their providers; and ongoing capacity building for public health organizations and their staffs.

To assist SERL and VDH in the implementation of THIS, the Transgender Taskforce (TTF) was formed to enlist community involvement in its process. The TTF began meeting in the fall of 2003 and became instrumental in a community mobilization process, informing the transgender communities of Virginia about the purposes of THIS and the opportunities to participate in the study. A newsletter was produced for circulation among providers and transgender residents of Virginia, to illustrate the work of THIS and the TTF.

The first phase of THIS reported herein examines the qualitative data collected from participants in the focus groups and builds on a presentation made at the Annual Meeting of the American Psychological Association in 2004 (Hendricks M, Bradford J, Xavier J, 2004).

### **Study Design and Methodology**

The principal research questions were: (I) what are the risk factors driving HIV infection, and (2) what are the social determinants (race, class, education, employment, etc.) of health status among transgender people in Virginia? Secondary questions included how transgender people currently access routine medical, transgender-related, HIV-related and mental health services in Virginia: what experiences have they had with their providers, what barriers to access have they encountered, and what are their service needs.

This first qualitative stage employed a rigorous topic-based approach, using focus groups to explore not only the psychological and behavioral contributors to increased risk, but also the impact of barriers routinely encountered by transgender individuals in attempting to access healthcare services. An exhaustive search of the available literature was conducted to examine both the methodologies employed by other qualitative studies and their findings with regard to the research questions. From this analysis, a four level conceptual model evolved to address the principal research questions. Social stigma was hypothesized to be a root cause, producing societal factors such as discrimination; low self-esteem; health care provider ignorance of transgender health; and the prioritization of access to transgender-related medical services by transgender people. These societal factors produce mediating factors such as poverty, sex work, substance abuse, gender identity validation through sex, and provider hostility/insensitivity. The final products of these mediators are direct HIV risk factors including unprotected sex, lack of negotiation for safer sex, low perception of risk, IDU and viral transmission risks, lack of insurance and barriers to access to care.

From this conceptual model, nine question areas were developed into the focus group protocol, including:

- Access to regular medical services
- Access to transgender care services
- Employment discrimination
- Housing discrimination
- Violence
- Substance abuse & self-esteem
- HIV knowledge & perception of risk
- HIV testing
- Access to HIV/AIDS treatment services

Eleven drafts of the focus group questions were developed and revised, including input from an experienced group of transgender health advocates and researchers. The final focus group protocol (see

Appendix Two) was submitted to the VCU Institutional Review Board in December, 2003. A combined pilot testing and focus group facilitator training session was conducted on January 14, 2004. Transgender women and men of different ethnicities were trained as focus group facilitators, and they were assisted by SERL staff members who acted as co-facilitators. The co-facilitators were responsible for focus group session logistics, including tape recording and note taking. The focus group protocol included a verbal reading of the informed consent by each focus group facilitator, assuring that participation was completely voluntary. All participants were informed that no identifying information would be used in reporting the data. A financial incentive of \$10 was paid to each participant, and lunch was served before each focus group session.

Eligibility for participation in this qualitative study was restricted to transgender self-identification, Virginia residency, and age 18 or older. Study recruitment was conducted by regional coordinators who worked with the Transgender Task Force to promote the survey and alert potential participants to the locations, dates and times of the focus groups. The focus groups were conducted from late March to late April, 2004.

In order to assure diverse demographic and geographic participation, 10 focus groups were originally planned. However, two groups were cancelled due to lack of participation, and one group drew only one participant. The qualitative phase was completed by the end of April 2004, with a total of 7 focus groups and one solo interview, for a total of 48 participants. The transcripts were then encoded for analysis using a special software tool for qualitative data, NVIVO Revision 2.0.163 (QSR, Incorporated). The results from the demographic questionnaire were entered into SPSS Version 12 for Windows.

### **Study Results**

Study Participants

The seven focus groups conducted included three for Male-to-Females (one white, one Latina and one mostly African-American); three for Female-to-Males (all mixed ethnicity); and one rural group of mixed gender vector and ethnicity. There also was one solo interview with a white MTF. The observed demography of all participants (n=48) is shown in Table I. The demographic figures for Table 2 represent those participants who responded to the questions of the Demographic Questionnaire (n=27). Only valid percentages are shown.

Table I: Observed Demographics of Participants (n=48)

	Frequency	Valid Percent
Race		
African-American	25	52%
White	18	38%
Hispanic or Latino/a	4	8%
Other	I	2%
Assigned Sex at Birth		
Male	30	62%
Female	14	30%
Intersex – assigned male	2	4%
Intersex – assigned female	I	2%
Missing		2%

Table 2: Responses to the Demographic Questionnaire (n=27)

	Frequency	Valid Percent
Age		
19-29	14	54%
30-39	6	23%
40+	6	23%
Present Gender Identity		
Transgender	16	59%
Woman	5	18%
Man	5	18%
Other	I	3%
Sexual Orientation		
Queer	9	33%
Gay	8	30%
Heterosexual	5	18%
Bisexual	3	11%
Questioning/Asexual	2	7%
Education		
High School Degree or GED	5	18%
Some college (no degree)	6	22%
College graduate	8	30%
Some graduate school	I	4%
Graduate/Professional Deg.	5	18%
Technical school	2	7%
Income		
Less than \$10,000	5	19%
\$10,000 to \$16,999	6	23%
\$17,000 to \$24,999	4	15%
\$25,000 to \$35,999	3	11%
\$36,000 and above	7	27%
Employment		
Full-time	18	69%
Part-time	4	15%
Unemployed	4	15%

Of those responding to the Demographic Questionnaire, 90% spoke English or were bilingual and two spoke only Spanish. Nearly 90% were U.S. Citizens and only four had immigrated to the U.S. While living in Virginia, forty-eight percent had lived in an urban area, 22% in a suburban area, 18% equally in urban and rural areas, and 11% in a rural area. Forty-one percent were in a monogamous relationship, 22% in non-monogamous relationships, 26% were looking to be in a relationship, and 7% were not looking for a relationship.

### Access to Regular Medical Services

Although this section asked about regular medical care, the participants mostly discussed their access to transgender care services, reflecting its importance to them. Lack of health insurance was a commonly reported barrier to access to health care by many participants, especially transgender women of color. It was often linked to lack of employment, which was often a product of discrimination.

"In order for you to get insurance, you have to get a job first, and for a transgender it's really hard for you to just walk in to apply for a job and the person that's interviewing you actually wants to know if you're going to get along with the people that already work in the job, instead of saying maybe she's qualified for the position."

"You have so many girls that cannot receive any type of insurance ... that work the streets. ... They can't receive insurance because they don't have jobs ... they're afraid to try and get jobs because they want to live as women... so it causes them to go without a lot of things [healthcare]."

Lacking insurance, some participants did not have regular doctors.

"I haven't seen a doctor since I moved here eight months ago, and I've needed care for stuff that could've been taken really easily with a primary care, but I didn't have (a doctor), so I ended up in the ER a bunch of times, and paying out of pocket for some of that, paying out of pocket for hormones, but mostly it's the not having been checked out in a really, really long time that's scaring me."

Generally, white participants fared better than participants of color with regard to having health insurance that covered their health care. However, even those who had insurance experienced difficulties when it failed to cover their transgender care services.

"Everything beyond my prescriptions is not covered by insurance, and I fight with my insurance company over the rate at which they compensate me for seeing my endocrinologist because he is outside their particular system... they do not have a referred endocrinologist for transgender issues."

"I've pretty much given up on getting insurance companies to cover like hormones or anything."

Due to insurance problems, some participants could not find doctors to treat them with hormones.

"Because of the conflicts in insurance, I called (many doctors') offices... and said do you have trans patients? Can you tell me a little bit about how you work with trans, and they were like either hostile or clueless, and so I just stopped."

One participant noted that everything changes with HIV infection.

"My opinion is a lot of the girls, they don't have the means to find employment to receive (health insurance) benefits. Unless down the road they find out that they're positive, and they are able to receive a check at that point."

Some participants had identity documentation difficulties that prevented them from getting the care they needed.

"If your job thinks you're a man, but you need gynecological care, and you're signed up under your insurance as male, so you don't get your gynecological care covered."

"Having your name legally changed makes a difference. Because a lot of times, insurance, they don't know you personally, but just having a female name, they're going to associate that with being female."

One participant had the same difficulties even after a name change.

"Although I changed my name, I was still with the same insurance company, so they were still dealing with (my male name) versus (my female name). So having the name change really did not matter, they were still giving me what they would have offered (me) as being a male."

For some participants, obtaining insurance became an issue since it involved disclosure of their transgender status, which put them at risk for job loss.

"Do you come out at work, (and) come out on your insurance company, do you call them up and say there's been a mistake, or do you just pay for your gyn stuff out of pocket and hope nothing's ever wrong. I know that was always a big issue. Last year I changed jobs twice, and I had to make that decision twice. And both times I chose what I knew work was looking at me as."

One FTM participant expressed fears of losing his health insurance if his transgender status became known to his insurer through his doctors.

"If they prescribe me hormones, they don't have to put me down as (having Gender Identity Disorder), or as any way that would disclose me and I would get kicked off the plan. So all of my gyn stuff is covered, but all of my trans stuff isn't, including hormones (and) blood tests."

The participants' care experiences with their doctors were mixed. Fear of a hostile or insensitive reaction led some participants to not disclose their transgender status to doctors they did not know well. Those who were out to their doctors were comfortable with them, and they tended to stay with the same doctor who knew their transgender status. However, some participants mentioned hostility and lack of respect for them as transgender people as a barrier to access to care. Their experiences reflected their providers' ignorance of transgender people and sometimes frank discrimination.

"The doctors don't understand the transgender community... They want to be seen as women, and they want to be able to come to [doctor's offices] and be accepted, and lots of times they aren't because of their physical appearance."

"(The) last time I went to the doctor, this woman closes the door and then starts just like chewing me out because of my appearance, (she) just totally reamed me, and I (said) I just wanted you to look at my back so that I could work. And she didn't even address that, she was just like oh, you're fine... I hate going to the doctor."

Some participants had such bad experiences due to the insensitivity of doctors; they avoided being seen for treatment.

"Some girls do have insurance and some don't, but when they go to care, the physicians feel like they have to call them by their legal name. And if they're dressed as Betty Jo, but their legal name is John Doe, they're not going to get up, they're going to wait for things to die down, and then they're going to walk out. And a lot of them are lost to care because of that."

Many female-to-male participants had some particularly difficult experiences when trying to access gynecological care.

"So I'm sitting there in my boxers, and the woman (doctor) comes in and says to me, 'Are you in the middle of a sex change?' like just flat out... I said yeah... and then she said, 'Well, I don't know how this works, do women have penises sewn on?' And that was the first thing she said to me, and I was sitting there with no clothes on... Oh my God, you know it was really horrible. I was stuck here at her mercy, and I need this care, but I've got this crazy woman in the way."

"I don't know many (who go) to a gynecologist, but that's already a pretty miserable experience in my mind. When I'm there, I'm not necessarily in my best state of mind to be asking whatever questions I might have or reaching out for help or assistance. I don't necessarily want to talk about how I have sex, because this person might be thinking it's weird that I have the genitals that I have. I don't want to be paying any more attention to it than I already am, by having them do their thing in there."

Some doctors even incorrectly identified the participants' transgender status as the cause of their medical problems.

"Once they find out that you're transgender, any other illnesses that you may have, they don't tend to address them as strongly as they might if you weren't transgender because they (believe) that that is your main problem, and that's something's wrong psychologically with you."

"Well they didn't know that I was F to M, even though the forms I filled out said I am legally female... They had me take my shirt off, which was not comfortable for me at all, and when they realized at that point that I am female, they assumed that that was the cause of any problems that I could have had, when it was an entirely unrelated situation."

### Access to Transgender Care Services

Since transgender-related medical care (hormone therapy and surgery) is not yet viewed as medically necessary by most doctors and nearly all insurance companies, most participants experienced

barriers to accessing it. Yet most of the participants felt it was a high priority need for them. One participant summed up the importance of this need.

"My experience has been that people not only buy hormones everywhere they can possibly get them, but they are willing to do almost anything to get them. They're willing to sell themselves often, and sell their life to feel better about themselves."

Lack of insurance was again mentioned by some as a barrier to getting transgender-related care. While some insured participants were fortunate to get their hormone therapy covered by their health insurance, many mentioned the failure of their plans to cover it and also cosmetic procedures viewed as elective by their insurers.

"Some things are covered, some things aren't."

"Even the girls that are lucky enough to obtain insurance through employment benefits, a lot of times they're not able to use that insurance where transgenderism is concerned, because we know that a lot of the processes we go through to transition entail cosmetic surgery, and most insurances don't cover that."

The lack of insurance, having insurance that did not cover transgender-related care, and the expense of paying for it out of pocket were common barriers to access.

"I think the biggest problem most people have is paying for it when it isn't covered. It's generally been not too difficult for me since I've had good paying jobs, (but) there's months here and there where all your bills get a little bit higher and sometimes it's difficult."

"I do know of people out there who can't get the care because they just don't have the money, period."

The lack of willing local providers frustrated many participants.

"We need to pull together to find these doctors that are caring, that are willing on sliding scales."

"I hear you. It's just no resources. There's nobody in town."

Some participants went out of state to get their hormones.

"We used to go to a place in D.C. and get shots. Drive all the way to D.C. and get shots."

Most participants knew about self-medication with transgender hormones. They either did it themselves or knew of friends who got their hormones on the streets, from friends or through the internet. When asked if they knew anyone who has received hormones from someone other than a doctor or licensed healthcare provider, one participant simply answered "everyone".

"I'm out on the streets. And on the streets you pay for your hormones and you do street treatment."

"I've known people (that) it wasn't so much a money issue as they were simply afraid to talk to a doctor, so they simply read on the internet what the drugs, kind of back door, and self-medicated, you know, just choose a dosage and self-medicate."

Some MTF participants rationalized self medication due to their lack of insurance coverage and the constraints of the Standards of Care<sup>2</sup> of the Harry Benjamin International Gender Dysphoria Association (HBIGDA). The Benjamin Standards largely govern access to transgender-related medical care by middle class transgender people and are often viewed negatively as a gatekeeper system by many of them.

"The insurance will not cover it, and there's a lot of requirements before you can start the process with a legal doctor. So you have to go with the second option, which is getting illegal hormones from other people or from other people who have already had the treatment. So as a transgender, I have (done) that, and I wouldn't like for the people who are starting to have to go through that, that's why we're asking to have some more support from the state on this issue."

"(Since) the insurances will not cover that treatment, it becomes very expensive, so transgender people will always have to look for second options, which will be cheaper and faster for them, and will not have to go through all that headache and trouble of getting hormones (through a doctor)."

Some FTM participants mentioned sharing their testosterone in the context of friendship. Although testosterone is administered primarily by injection, needle sharing by FTM participants was not specifically mentioned, although it may have occurred.

"If a friend of mine who ran out of insurance is like on T (testosterone), needs the T, asks me for it, okay fine. You know, okay, I can do that for you."

"I haven't done it myself, but I do know people who have done it, and I mean, I don't know what you'd call street T (testosterone), but you know, if I have a prescription and my friends (ask) 'can I just have a shot', you know, that kind of stuff happens a lot."

However, many participants were aware of the dangers of self-medication.

"One friend of mine was taking an enormous dosage, and when I found out what she was taking, I told her you really need to see a doctor, and she credits me with saving her life, because ... her blood pressure had gone way up."

"If (there) was a way for... hormone or silicone treatments to be offered through a doctor, through a physician, at affordable rates, that would eliminate a lot of transmitted diseases or anything like that, because that's very unsafe and unclean."

Injection silicone use was popular among most African-American and Latina transgender women participants, as an adjunct to or replacement for hormone use. Unencapsulated silicone injections were

<sup>&</sup>lt;sup>2</sup> The Sixth Version of the Harry Benjamin International Gender Dysphoria Association's Standards of Care for Gender Identity Disorders is available online at <a href="http://www.hbigda.org/soc.htm">http://www.hbigda.org/soc.htm</a>

banned by the U.S. Food and Drug Administration in the 1960s as a serious health risk.<sup>3</sup> The most common reason given by participants for their injection silicone use was the speed of physical transformation, which seemed to be linked with immediate improvement of self-esteem.

"(I) personally have gotten silicone injections, and the reason that I got them is because the hormone process took too long. And I wanted what I wanted then, and I wanted my results immediately."

"The process of taking hormones can be so long depending on your body taking on that medication, and some girls, they want instant breasts, they want instant hips, they want instant facial work, so they're not going to take the time that the hormones can take. They want that instant gratification, so they go with the silicone."

One participant mentioned that some do silicone injections exclusively.

"I would say within our city... we have many girls who only do silicone injections. We've had girls who have come here from different cities to get the silicone, and I think the purpose of a lot of the girls receiving it is because its instant, it's giving them the gratification that they're looking for instantly, so they don't want to sit back and go through all that it would take to go through legal aspects. Because they want it now. It's about getting it now, it's about being able to show it off now, so that's what the girls want that would cause them to consider taking illegal hormones or doing illegal silicone injections."

Another participant mentioned peer pressure.

"A lot of them are young, and they're being peer pressured... more of the younger children are doing it because they're telling them 'oh you look so flawless, and if you get this done, you're really going to look (even better)."

One participant mentioned the lack of insurance as a factor.

"And we go back again to the insurance issue. The way you can go legal is implants. But when you cannot afford implants, what is your second option? Silicone injections. So, that's why most of the girls choose to do that. Again, because we don't have the support of any state or health insurance that would help you afford the more healthy, legal methods"

Silicone use also improved the desirability of transgender women who do sex work in a competitive environment, but it may result in their inability to obtain other employment.

"Like she was saying about a girl with a flat chest, and the girls who are more round, it does become competitive. And that's another reason why a lot of girls don't have jobs... They get all this stuff for the men on the street who mean nothing to them and think nothing of them, and then... they look too abnormal to work in the daytime. Some of it is good at night, but then you can get outrageous with it, and if you look a mess in the daytime, don't nobody want to hire you because you're such a spectacle."

"A lot of the girls are involved in street walking and prostitution, (and) it's become very competitive on the streets. The hormones and silicone are just a way of improving yourself and

<sup>&</sup>lt;sup>3</sup> Gender Education & Advocacy (2003) Silicone Use: Illicit, Disfiguring, Dangerous. Medical Advisory Bulletin, August 22, 2003. Available online at: <a href="http://www.gender.org/advisories/silicone.html">http://www.gender.org/advisories/silicone.html</a>

marketing yourself toward that industry, because the girls that have had more work and visually look more feminine and rounded are the ones that the johns are approaching more. So they're more marketable, and they look the part, and the men want them more."

Injection silicone use was not restricted to transgender women participants, according to one female-to-male participant, who spoke of its dangers.

"I know a lot of transgender people, female to male, male to female, it is hard, and they're left to (getting) it on the black market. So and so here has silicone, so I'm going to go here and get my face pumped or get my pecs pumped, and that oftentimes frightens me, because anything could happen. Just like you can catch a disease getting a tattoo in somebody's basement, or piercing your ears, getting silicone from whomever on the street is just as dangerous, but it's something they feel that they need to do, that helps them to feel comfortable with who they are."

Although there was no direct mention of participants' sharing needles for silicone injections, it may have occurred.

### Access to Mental Health Services

The participants expressed both positive and ambivalent attitudes about mental health care. Those who had psychotherapists were generally happy with them, and they accepted the requirement for psychological evaluation prior to referral for hormone therapy. However, some had had negative experiences with their psychotherapists, who had treated them very poorly, due to inexperience and/or bias.

"You can't report the depression or the anxiety that you're feeling, because if you do, no one is going to see you as far as seeing a transgender person, because they're going to think you're suicidal."

"Worse yet, we get treated with derision by professionals... this might not be something in their everyday experience, or something that they've done any reading on since graduate school, but (they) still end up treating transgender patients with a certain contempt that is really unacceptable."

Some psychotherapists still viewed transgenderism as a mental illness.

"My own experience (with mental health care practitioners has) been completely negative. I would say over the years, I'm 55 now, I've probably spent most of my adult life in some kind of therapy or another. And I'd say in every instance except maybe one or maybe two, I was told that I was either very sick or something comparable to that. It was always a problem. It was never like this is something you obviously need to do. It was always the opposite, like this is something that you shouldn't be doing and you've got to stop."

One transsexual participant was devastated when his psychotherapist failed to refer him for sex reassignment surgery. The therapist's actions seemed to indicate a lack of experience and/or lack of competency in working with transsexual clients.

"It's like he didn't do his homework, it's like he didn't realize what he was agreeing to write (for) me, like he didn't look it up in the dictionary. And when I got there, I was like okay, session's over, where's my letter? (He said) 'um, yeah, about that, I found out what that means, and I don't think I'm really ready to write you that letter. I feel that I can lose my licensing over that, and I'm sorry, you're going to have to find a different therapist because I'm not your man.' And then he proceeded to like break me down mentally and emotionally, and I just cried for like hours, and I was totally destroyed."

Those participants who had not seen a psychotherapist had negative attitudes towards mental health care, which seemed to originate from the stereotypical social stigma attached to seeking mental health care. There were also some who felt that being transgender was not a mental illness, and expressed resentment.

"I just have issues with them treating who we are as a mental health issue...I'm not crazy. This is just who I am...I didn't go to a mental health (provider) because I didn't have a problem with my mind. I feel that us complying and going to mental health (providers) only contributes to what (the State of) Virginia says, (that) we're crazy. I'm not crazy. I don't feel like I need a (psychological exam) because I'm a man who wants to be a woman. I'm a man who wants to be a woman who wants to work every day."

An African-American participant noted a racial difference in mental health access.

"I think the services, they're being used, they're just not being used in the transgender of color community... the white transgenders are using them to the fullest. We're just not getting out there and using them."

Another participant explained the African-American cultural taboo of seeking mental health care.

"I don't think they even considered getting any kind of mental health because of the stigma of mental health... It's negative, any kind of therapy is looked down upon, I guess because it's learned behavior, that you have to be crazy to have any kind of mental health (care). And I believe that happens a lot in the African Americans, you know, from way back... I think it goes back to the African American family. In a lot of families, you don't tell anything that happens in your household. So why would we go tell somebody and pay them? So mental health is not an option."

For many who sought psychotherapy, finding mental health providers who were compassionate, experienced and competent was very problematic for them.

"I've heard absolute horror stories of people just trying to find a local therapist through the phone-book or whatever, and getting all sorts of horrible advice."

"If you live out in the country...there's just nobody out there that's available that understands the issue."

Some participants mentioned their support groups as an information resource where they could get a list of experienced psychotherapists, while others mentioned the benefit they received from their peer support groups.

"We talk in our support group on Mondays about letting the girls know if they're not knowledgeable about what sorts of things are out there, ask someone. And it's okay if you can take the time to ask someone ...how can I get these resources that are out here to get these hormones and go through the proper things I need to live as a woman."

### **Employment Discrimination**

Employment discrimination and difficulties in employment were common experiences among many participants. Four of the 27 participants answering the Demographic Questionnaire felt they had lost a job because of being transgender, with another three unsure, though they may have.

"I know personally two people who were very quickly fired when they came out."

In addition to job loss, many participants experienced discrimination when they applied for jobs and did not get hired. In many cases, the discrimination was obvious.

"I've applied for so many jobs, and unfortunately, they don't look at my resume, they look at what they see in front of them... I feel that's totally unfair, because if you're qualified for the position that you're applying for, they should look at your resume, they should not look at your appearance (or) your gender."

"I have a girlfriend (who worked) at Pizza Hut. And they have other gay people that work at Pizza Hut, but being that she's transvestite, they (made) up a lot of excuses to get rid of her, and they finally got rid of her, and didn't really give her a reasonable excuse why they're getting rid of her. It's just a lot of that goes on."

An inability to pass in one's chosen gender was often linked to job discrimination.

"I have heard of other transgender girls who have been discriminated and have not gotten the positions because of their physical appearances or because they later found out that they were transgenders."

"I have seen people experience (job discrimination) because of their physical appearance, and I think it becomes a little easier for girls that have a physical convincing appearance as a female, versus someone that does not have that physical convincing appeal as a female and causes a lot of problems... a lot of girls can never get through the door to live as women because physically they would never be convincing to the public eye."

One participant mentioned a difficult experience with job training.

"When you go and try to get job training... they try to tell you first that transgender people are like very sexual, so when you go to apply for school or a job, you try to dress down, and try to look very conservative. But once it comes out that you're a male, it's still a problem... It's just a problem with you being transgender."

Many of the participants had difficult experiences on the job if they were known to be transgender or in the process of gender transitioning. Usually, their behaviors or their non-passing appearance would disclose their transgender status. Hostile work environments, with harassment and sometimes physical abuse by co-workers, were reported by several participants.

"It just becomes clear that I'm different, and they pick it up. It's almost like you can feel it, just feel how they look at you, how they don't include you in their talks and stuff, and you start becoming marginalized, and it makes it hard to do your job... It usually devolved into at least verbal abuse, but sometimes it would get physical, like people would throw things at me or whatever. If I wasn't fired, I would usually start making plans to get another job, and then the cycle would start again."

Participants who worked in the blue collar trades seemed to face the most harassment. Getting transferred to a more difficult position and getting hazed into quitting a job was reported by some participants.

"Sometimes what happens is you get moved to another job that's a dirtier job sometimes because you are a female, and I guess sometimes they're trying to see if they can break you, I believe, make you quit. And what happens sometimes is we don't quit, and then they finally give up. "

Generally, those in white collar positions, with employment longevity and/or who were good at their jobs, were more fortunate in keeping their jobs when they came out as transgender.

"I started off by telling my closest girlfriends and my assistant, and then my direct boss, all over individual lunches, then talking to human resources, then bringing out my therapist to talk about transgender issues in a presentation to the whole company, making myself available to talk to everyone, everyone made a point of coming in and talking to me... It worked out extremely well, but it was also based on a lot of communication, I put together a lending library so that people could come and read things, I gave them a lot of on-line resources."

"They're with me all the way. They know my work because I've been there for 16 years and they also understand loyalty, which I wasn't really sure would pay off. So I have had for myself just a very easy time of this."

The sex workers among the participants were mostly transgender women, but there were also a few FTMs. They had complex, often interrelated reasons for doing sex work. For some, regular employment was too hard to get because of discrimination, fears of discrimination, or fears of lack of acceptance in a routine job.

"I think that's why you have the large number of transgenders who walk the street corner or hustle or date... because they can't find work doing legitimate stuff."

Economic vulnerability was given as a reason for doing sex work by one participant, who also mentioned the threat of STD transmission.

"Nobody wants to be out there, but if you want to eat, and you don't have your hotel money, you're out on the streets, you've got to go out there and get it. So if you're sick, then ten more people are sick. (That's) another reason to get the girls off the streets and into jobs and housing because they don't have to be on the streets."

Another participant felt it was an easy, fast way to make money.

"With me, I don't feel as though I was forced into working the streets. Of course it made my desire even greater knowing that money is there instantly. It's not like waiting a week or maybe two weeks or whatever. It's not because I felt like that was all I could do. But just the dollar bills, and being in your eyes, knowing that I could go out and get it. Just that quickly."

One participant linked sex work with being able to earn the money to transform her body.

"Being a transgender is an expensive life, and most jobs that we can get is not going to do it. You've got to have some extra income, you've got to have some fast money. The regular job, you can't pay your bills and change your body and be a woman."

Another participant spoke of having her gender affirmed, of being in control, getting sexual gratification and not having to deal with lack of acceptance in a job.

"This is an easy way to have a man attracted to me... you're out there, (with) other people like you, on your own particular terms... and it's also sexual gratification. It's a little bit easier than going up to a 9 to 5 job, dealing with everyday ridicule..."

### Housing Discrimination

Housing discrimination was not widespread among the participants, although it did happen to some. Victims of housing discrimination were mostly African-American and Latina transgender women, and some of them mentioned discrimination in public housing and shelters.

"I think there's much discrimination against transgender community (in) housing in this area in particular because there's no housing options offered specifically to transgender people. I know... they have no shelters that will offer to accept transgenders in this state, they have no form of transitional housing to address transgender needs. If a transgender individual needs housing, they're placed in a situation with heterosexuals who clearly won't accept them, or will make it hard for them to live in that sort of dwelling, which eventually forces them out."

"A friend of mine right now is going through the situation now where (she's) homeless (and) went to the men's shelter. The men's shelter said she couldn't come there because she would be raped by the men. She couldn't go to the women's shelter because she wasn't a woman. (So she) had to actually live in the park."

Some participants mentioned the stigma associated with being transgender or transsexual (itself related to sex work stigma) as a barrier to obtaining housing.

"Here in Richmond, we're automatically labeled trouble or prostitutes, or we're going to create a situation with the other tenants, so they won't rent to us. Not knowing us as a person or what the situation might be. They don't know our back history. It's just that the label Richmond has with transgender people is drug addicts, prostitutes, and whores."

"When they find out you're a transsexual (or) transgender, trying to live in certain buildings, they automatically think of a transsexual's reputation to be a party girl or to be just not good for the neighborhood. So they will actually deny your application. "

One participant mentioned being denied housing after providing his legal identification.

"Before I moved in my place, I went to another place and I put on the application my name because it's legally changed. (The rental agent) called me and told me I had the apartment. Then when I went (in), she went to print my identification card and she said 'they made a mistake on your ID and they put male,' and I said no, I am a male. And she changed the whole subject and (then she) told me I was approved, (and) I didn't need a co-sign or anything. (Afterwards) she did that she called me back and she said... your credit isn't good enough. And even when my mother was going to sign for me, she still just didn't want to help me as a tenant."

Besides discrimination, other types of housing difficulties were reported. Many participants had landlords who did not discriminate against them, but reported their housing choices to be severely limited. Once they found housing, they tended to live there for many years, even if it was inadequate. Some participants lived together as roommates, and others lived with friends or family members. Some participants linked employment difficulties with a lack of housing opportunities.

"(Working) at a minimum wage occupations... makes it harder to build the credit or be able to show some type of proof of their actual occupation or job. (So) it's harder to be able to rent an apartment, (or) get a loan for a house..."

"I have heard that many transgenders don't apply to get a home because they don't have employment and therefore they cannot apply."

### Violence

Violence was widely reported among the participants. Of the 27 participants who completed the Demographic Questionnaire, 15 reporting having been victims of violence or crime. The types of violent incidents most often reported were intimidation (9 participants); verbal or sexual harassment (9); sexual assault/rape (4); and assault without a weapon (4). As perceived by victims, the most commonly-reported motives of perpetrators were homophobia (10 participants); transphobia (7); material/economic gain (5); and domestic violence (5). There were many personal experiences with violence, with participants who spoke about being shot, stabbed, run over by cars, beaten with fists and feet, etc. Many also had been robbed of possessions and money. Murder was commonly reported.

"I have friends that have been gay-bashed or attacked because individuals later on found out their real sex. (It was) not that they were trying to hide it or anything. It was just that they were living (their) lives as females, from males to females... I have friends who have gotten killed because of being transgender."

"Yes, I do know people who have been killed, I know people who have been attacked just for the fact that they find out they're actually a transsexual."

African-American transgender women sex workers seemed to experience the most violence.

"We had two girls, both of them got shot, one got killed, we had another girl who was out working who got cut up. We had another girl maybe seven or eight years ago who was killed on a bridge. They've been shot. They've been beat up."

"I've had bad experiences when I worked on the streets. I've had guns pulled out on me. I've had a guy that punched me in my head before. I've been robbed before."

One white participant spoke about being sexually assaulted twice.

"I've been raped a couple of times, (when) I was a prostitute and they found out...One beat me badly and raped me, (and the other) just raped me. And I have heard of transgenders getting killed if it's been found out (that they were transgender)."

Some participants talked about the issue of disclosing or not disclosing one's transgender status to a sex work client before having sex with them.

"I think what happens is sometimes transgenders have sex with people and they don't tell them they're transgenders. So when the person finds out, they just freak out."

"Safety is a huge factor (behind) disclosure or nondisclosure (to sex work clients)... I think even within trans communities, there's a huge debate about disclosure, and kind of an assignment of moral judgment around it... If somebody takes you home, or if you bring someone home with yourself, and then you don't disclose and there's violence, that's your fault. And that's a judgment that law enforcement throws on you, that the trans community can throw on you, non-trans feminists... You kind of get it from all different sides."

One sex worker assumed that by working the transgender stroll, she was safer because her clients would know she was transgender.

"When I first started going out, the area that I was going, I just kind of assumed the men out there knew... but I found out one night that some guys out there really don't. And I had a gun drawn on me one night because the guy just simply didn't know, and he felt like I had tricked him or something, and that was kind of scary for me. I guess I was kind of thinking that everybody knew."

One FTM participant spoke of the necessity to pass in order to avoid assault.

"It makes you feel like you have to hide, that you actually have to keep it secret, or make yourself seem like you blend in with the straight community so that these things don't happen... I've accepted who I am, and I've made myself this way... But if they look and they see, 'oh you've got hair on your face and you're supposed to be a woman,' you'll get assaulted for that."

Many participants also spoke of harassment and intimidation in their own neighborhoods.

"My first couple of times coming out through the neighborhood and just dealing with the ridicule and the people throwing rocks, people throwing eggs and stuff... A lot of people will really, really push the issue and will really, really try and harm a person (who's) transgender. A lot of times people will like wink, they feel like we're scared and we're not supposed to say anything back, we're just supposed to take whatever they dish out to us..."

A few participants talked about fighting back and defending themselves, since they had difficult relationships with the police. Many participants complained about secondary victimization by the police when they reported the violence.

"I know of many cases that have not been reported to the police because they feel that the police would not actually do anything to protect them. I have seen cases in which they have reported it and once the police arrived to the scene and finds out (they're transsexual)...they start acting differently, and they don't even want to deal with you."

"They fear that they (will also be) thrown in jail, (and) the person who attacked (them will be) released right away or after a short time, and then they are again at risk being a victim (because they reported it)."

Some participants reported discrimination by the police, including being blamed for their own assaults.

"They make fun of you. Instead of them helping the transgenders, they're even making it worse (by) making it like it's the transgender's fault for getting beaten up..."

"They (the police) consider (us) male to male, not male to female."

Secondary victimization also occurs in the court system.

"I've been to the cases... and I've seen how they actually didn't really punish the person like they was punished because the people on the jury or whoever might say well this was transgender, you lead this person to kill you because you fooled them. And that's exactly what they tell you in the courts when you go for these charges, and it actually gives leniency to the person who done the crime. And it makes... other guys feel like okay, we can go kill this fag because they really don't give out that much time for killing faggots. That's actually the message that they send out in the courtrooms when they go to get sentenced."

### Substance Abuse

The participants reported high levels of substance abuse. Specific drugs mentioned by the participants included alcohol, marijuana, crack cocaine, cocaine, PCP, ecstasy, pharmaceuticals, inhalants, and heroin by injection and nasal ingestion. Tobacco use was also reported by some participants. There were many active users, with alcohol and marijuana most often mentioned by them.

"I mean I definitely have a drug problem – I know it. I don't know if it's a problem, but I definitely have an active using lifestyle but with marijuana. It's not an occasional thing at all."

The reasons given for using or abusing alcohol and drugs were often interrelated. Many participants mentioned the lack of societal and family acceptance, the stress it caused, and its impact on their self-esteem. Using drugs and alcohol is a means of dealing with all of these stressors.

"I think the majority of transgender individuals that I've encountered that do a lot of drugs and alcohol because they're not being accepted (by society). A lot of times (it's) their family situations, and it's (also) a lot of peer pressure. A lot of these things tend to cause them to drink or to take drugs just to feel good and have a moment to forget."

"I (used) drugs and alcohol to medicate my feelings, and feeling worthless, not being accepted by my family, the people on my job, society..."

A few participants connected employment discrimination with drinking and drugging.

"I believe that the use of drugs and alcohol is mainly related to the job situation, because if you are discriminated against, if you have no hope, and if you have all this fear and anger inside, you try everything to drown it."

Some participants talked about the depression they suffered when they first realized they were transgender and drinking and drugging to deal with that depression.

"In the early stages of learning and coping with it, I know a lot of people who (did alcohol and drugs) in trying to cope with depression or that angst. I myself at one time wasn't an alcoholic, but probably an abuser, and I know a lot of people who have been very depressed and easily got addicted to things to treat depression."

Other participants attributed substance abuse to internalized transphobia, manifested by a lack of self-esteem and self-acceptance.

"It is a part of self-hatred, it is a part of low self-esteem... with anybody that's transgender, (I think it has a lot to do with) self-acceptance."

"It's a lack of loving themselves... People who use drugs or abuse their bodies all have the same thing in common. You can't love yourself if you want to do that."

Some mentioned drug and alcohol use as a substitute or replacement for psychotherapy.

"Instead of going to a psychologist or psychiatrist to tell them their problems, they think that by using drugs or drinking alcohol, their problems will go away. (But) they don't know that they're making it worse by doing that. Because the state at the moment is not providing psychologists or psychiatrists for transsexuals to go to."

"Most of the times, unfortunately for transsexuals, it's drugs and alcohol... they have access to it faster and easier than they would if they had to go to a psychologist, or if they had to go through a state or a mental health department."

Several participants mentioned a connection between sex work and drugs, and using as a means of coping with the pressures of sex work.

"From the sex workers that I know, there's a lot of marijuana and ecstasy use and abuse... Is it a coping mechanism with being a sex worker or being transgender? That's where I don't know (if) you can make that division necessarily. Clearly their lives aren't all sweetness and light, and so it's kind of an escape mechanism..."

Some of the participants were no longer active users and had entered recovery. Among this group were those who were struggling to maintain their sobriety. They expressed how their twelve step groups really helped them.

"Drinking has been a big struggle for me, and I think part of that has to do with coming to terms with gender stuff and all that... I'm in AA now and not drinking, and that's definitely helped me a lot as far as like getting on dealing with the transitioning issue and stuff like that. Instead of just stewing around in it and being frustrated with it and drinking, now I'm actually clear-headed and moving on with it."

Some participants also spoke about how self-acceptance, coming out and entering transition had helped them in their struggle to reach sobriety. Gender transition eased their depression and reduced their need to drink and drug.

"I actually had huge drug problem, and I used to drink insanely. And as soon as I started to pass, I felt better about myself, and it just seemed like I didn't need any of that any more."

"I had a big drinking problem that I couldn't stop. I've been to rehab and stuff, and I couldn't, and honestly, I tried and tried, and I couldn't, and once I started coming out and dealing with trans, I just naturally drink less. I'm more interested in being sober. And I still drink a little bit, but I don't feel I have a problem anymore. I mean I'm aware of it, but it's like that became such a second issue... I didn't go through rehab, I didn't need anything, I just went through withdrawal on my own, (and) sobered up pretty much."

### Self-Esteem

The participants' comments about substance abuse were often linked to their lack of self-esteem. The ultimate means of improving self-esteem was passing in their chosen genders, especially for most of the transgender women.

"I think (passing) is really important for girls to (be) able to be in public. If you're trying to be a woman, to be as convincing as possible because it builds your self-esteem, I truly believe that."

"When you don't see yourself physically as you do mentally or psychologically, I believe that it brings your self-esteem down. Once that transformation has occurred, then I believe your self esteem goes up... because you are able to blend in with society, and be accepted or tolerated by society."

Passing was most important for those who had gender transitioned or were in the process of transitioning.

"The goal of being a transgender is to be passable."

"I think the feeling of being free is gained there, especially (with) somebody who's been waiting all their life (to be able to pass)... I think self-esteem really kicks in when I get that acceptance from other people, and I'm not looked down on as somebody who is odd or funny, you accept me just for who I am."

For many participants, passing equaled societal acceptance, a normal life and a means of avoiding effects of the social stigma, such as ridicule.

"Nobody wants to be laughed at, and this is very serious, this is our life, and when you continue to be a joke or be ridiculed or whatever, it's just ugly."

"To me, it's a matter of dignity... and I don't want to be having confrontations with people all the time, I just want to go about my life, so passing makes that a lot easier."

Passing was also important for the self-esteem of the FTMs, yet some were ambivalent about being perceived as non-transgender men, possibly due to their experiences with sexism prior to their gender transitions.

"Even though I do pass all the time, and that's great, and I do like it, a lot of times I really hate it, because... I don't identify as a male, and people make this assumption about me all the time because I have those secondary characteristics that are making me a happier person... But socially, I want to be recognized as trans, but it never happens. I find that happens a lot with FTMs who transition, people don't spot it as easily, and I don't like being invisible like that, and I don't ever want to be just locked into the male culture."

Another FTM participant downplayed the importance of passing.

"I feel like I'm mostly comfortable, (so) it's funny to me when I go places to eat and people say sir, and inside I'm laughing, but it's just like okay, they really see me like a man. Some people realize it and some people don't... but I'm just like it's fine, it doesn't matter to me."

Since passing is subjective and creates a social hierarchy among transgender people (between those who pass and those who do not), it was a sensitive subject for many participants. One white transgender woman seemed to confuse beauty with passing.

"I couldn't give a damn about passing. If somebody comes up to me and says I'm the ugliest girl in town, I'll say well at least you got it half right. Because I don't really care what anybody thinks. I'll do my best to look my best, but if I don't actually fit in and have a nice symmetrical face like you, I am not going to worry about it."

Still other participants dismissed the importance of passing altogether.

"(lt's) no use worrying if somebody knows you're a man or a woman."

"I think you shouldn't let your self-esteem down when someone calls you out."

Having sex was another means of improving self esteem to many participants. Besides sexual gratification, it also affirmed their gender identities when they had sex with non-transgender men and women. Most of the African-American transgender women felt this affirmation by having sex with non-transgender men.

"It makes you feel more feminine and more womanly to have what you perceive as a masculine, domineering male figure approach you and accept you and go to bed with you. (If) he accepts (you), it boosts your morale, and it makes your persona feel gratified because you say I must be representing well. This big husky man chose me because I look like a woman."

"Yeah, it makes you feel real. It does. Because that's what you're transformed for, to get a man... when you meet a straight-acting masculine man to make you feel feminine like a woman. Regardless of what you all do under the covers."

Latina transgender and transsexual women also felt their genders affirmed by being in sexual relationships with non-transgender men.

"(When) heterosexual males are attracted to us... that will raise our self-esteem. (It) will also make us feel more comfortable in society and more accepted in society because we will be seen as a straight couple. Nobody needs to know what's in between your legs other than the person that you're going to be sexually involved with."

"Once you become involved with a heterosexual male, which is in fact what transsexual women are trying to accomplish, you will become more acceptable, you will become more of what you actually feel inside, and what you mentally are, a woman."

The wide variety of sexual orientations self-reported by the participants were not defined beyond their usual meanings, and therefore should be viewed with discretion for their implications regarding sexual risk behaviors. A transgender woman without surgery might view having sex with men as being heterosexual, while an FTM might resist the labeling of his relationship with a woman as heterosexual. One transgender man married to a transgender woman rejected other people's attempt at labeling their relationship.

"I met an MTF, so everybody looks at me and says now you're a gay guy, and I think if I'm a gay guy, what is she? She considers herself a woman. I consider myself a man. So I consider myself a straight man married to a woman. Well, the world has a different opinion, but I think my opinion should count."

For many transgender persons, gender transition is also a time of questioning and experimenting with their sexualities. Shifts in sexual orientation were not uncommon.

"Having formerly been a heterosexual male and now being a transgender person who dates men, it's just something where I was never a gay man, or I had never been in the position of being a man and being with another man."

"I know this (transsexual) woman, she's post op, and she recently had sex with a genetic male. And for her, it was pretty nice but it didn't ring every bell."

The Latina transsexual and transgender women spoke about their heterosexuality in strict terms, in that they would clearly be attracted to only non-transgender men as sex partners. Other Latina transgender women having sex with each other seemed to be unheard of.

"You are trying to match your mental feelings to your physical appearance. You are trying to become a woman, (so) of course you want a male as your partner. Being with another transgender person, interacting with them in the level of relationship, I don't think that is something that the transsexual community that I know of do, (or) have done."

"We are basically trying to accomplish what any woman would. We are trying to become a woman in every sense of the word, being that we will be attracted to heterosexual males. I personally am not attracted to homosexual males or transgender individuals... What most of the male to female transsexuals are trying to accomplish (is) a heterosexual relationship with a heterosexual male."

Gender identity affirmation through sex was also expressed by some of the FTM participants. One spoke about the importance of being accepted and affirmed by having a relationship with a non-transgender woman.

"If you are in a relationship, especially if that woman knows that you made that transition, and she just accepts you for the man you are, and loves you regardless, that would be the true acceptance. Especially if you can meet someone and you share your life together, and regardless if anyone else knows, the acceptance is really like the pinnacle of like okay, I am, I can totally be who I am and what I am, and whatever, and not worry about it, and somebody I can share that."

However, other FTMs who were in relationships with non-transgender men expressed the psychological stressors they experienced in their changing sexualities.

"I can tell I have issues, of maybe just not being able to just be a guy for a while. (I'm) going from straight to being a gay guy. There's nothing wrong with being a gay guy, its not like I have anything wrong with it, but all of a sudden I'm with a gay guy right away. I just want to be a guy and honestly not worry about my sexuality right now."

"I was in a relationship with a girl before I transitioned and I had to go through this whole sexuality crisis again... I started transitioning and of like oh my God, now I have to come out for the third time that I'm gay... But I still deal with this issue where I'm not out, I cannot come out to my parents again. I just can't. Like twice was enough. Like once as a lesbian, once as trans, I can't (say) by the way, I'm a gay man, because they're just going to be like what's next."

Disclosing their transgender status to male sex partners was also an issue for some gay FTMs.

"I date biological men and trans men, (and) I've had really good experiences but also some freaky times. You disclose, and they're like, they think you must now have a totally (awesome penis)... I've had some people where it's not really an issue at all, other people who are like score and they fetishize that and that's weird, or people who totally freak out."

"With bio guys, I know (FTMs) who... go home with somebody, having thought they fully disclosed, and having the guy freak out when they took their clothes off because the guy just did not get it. They freaked out or left or went on with (it), but had that little moment, and those are the things that I'm afraid of. So I think I'd prefer to have sex with somebody who is trans than somebody who is not trans."

### HIV Knowledge & Perception of Risk

HIV knowledge levels were high among the participants, and most knew the means of HIV transmission and common risk factors associated with it. Substance abuse was often mentioned as a risk factor, especially among transgender women.

"Substance abuse will always put a person in danger, because it always happens, if I'm under the influence, then the rules change. My behavior changes, my thinking changes. They always go hand in hand. You just can't get away from substance abuse and HIV."

"They feel discriminated and become stressed (and) depressed. When you become depressed, you go after alcohol, drugs. When you are under the influence of drugs and alcohol, you don't

care about protection, you don't care about sharing needles, you don't care about any of the facts that you already know of. "

Financial need leading to unprotected sex in prostitution was mentioned by several participants.

"(If your) financial need is such that if there's a client (who) just insists on going raw and for a certain price, when you're stuck in that particular stratum of society, then eventually you end up coming up with your own price."

"(It's) the money situation. A lot of them will pay you more to let them do it raw."

FTM participants spoke about having unprotected sex with non-transgender men.

"Especially a lot of random anonymous (sex) like blow jobs and stuff like that... There are (FTMs that) I know who have sex with men without protection..."

Despite the high level of HIV knowledge, perceptions of risk varied. Most transgender women thought their risk was equal to that of gay men, although some felt gay men were more at risk than they were. FTMs felt their risk was either equal to or less than that of gay men and transgender women. Only a few transgender women felt they were at higher risk than gay men. One participant noted that transgender women were are higher risk due to their sexual role.

"A lot of it is just mechanics. I would suggest that male to female transgenders are more than likely to be bottoms, and as such, they are usually the ones that are engaged in a riskier sexual behavior... It's just something where you're the one who's at extreme risk if you are in that sexual role."

Another participant noted that transgender women taking estrogen are less inclined to put condoms on themselves because of its effects.

"A lot of MTFs don't not want to penetrate, and they don't ejaculate if they're on estrogen and all that, it (affects) their prostate or whatever. "

Perception of HIV risk seemed to be the highest among African-American transgender women.

"I've always had knowledge and education of how to and where to and with whom. I know that it was taught to me that you should always think that everyone is infected. Therefore, you should always wear protection, whether you're giving or receiving."

However, another African-American MTF participant noted a difference in condom use between oral and anal sex.

"I think there are more people that are using condoms (with anal sex). I think a lot of girls still want to have oral sex without a condom... I don't mind saying it: I have oral sex without condoms. But anal sex, I will not do that without condoms..."

The use of condoms and other protective barriers varied across subgroups. African-American transgender women seemed to express the highest frequency of condom use.

"All the transgender people that I know that are having sex with men use condoms."

"I think transgenders use more protection having sex than straight and gay guys and everybody (else)."

One noted that transgender women sex workers used condoms because of their continuing need to work in the sex industry.

"I think a lot of the girls are using more condoms because if you're more of a street girl, you don't want to take the chance of not only catching HIV, (or) any other type of STD... If you're a true street walker, that's going to break your money bag if you're not able to go out and do what you gotta do."

Another African-American participant noticed an age difference in condom use and risk perception.

"I think maybe the older transgenders (use condoms), but the young ones, they haven't really seen people suffer like we have... from AIDS. The people they see with AIDS are still walking around doing shows, laughing and joking, so they don't take it as serious as we do. So I think they're more unsafe than the older transsexuals. Cause we've actually seen children suffer and die..."

The lowest level of condom use seemed to be among Latina transgender and transsexual women.

"Unfortunately, in the Latino transsexual community, not most of them use (condoms). Once again, we go back to the way that we're raised. If their men ask them not to wear a condom because it feels better, or because that's the way it should be with a woman, then they don't do it."

"In the Latino transsexual community, the way you are raised, you don't believe in condoms. You don't believe in protection.... (In) the countries that we come from, there is a belief that if you have a boyfriend, or if you have your man, you can have unprotected sex with him because he is your man. But you can have sex with other people if you're wearing a condom. And that's the other risk."

The reasons given by participants who did not use condoms included monogamy, substance abuse, denial of risk, fluid bonding, and cultural and societal factors. Being in a monogamous relationship was the most common reason, yet some transgender women continued to use condoms with their monogamous partner. Some FTMs refused to use barriers and condoms because they associated it with birth control, about which they apparently no longer worried because they were now men.

"I know some (FTMs) who have had sex with biological men (and) don't use condoms because they really don't get their period any more, and so they're not worried about that. It's really risky..."

Other FTMs spoke of their refusal to use dental dam barriers in the context of fluid bonding, a conscious strategy to reduce risk while having sex that's considered risky. In fluid bonding, sex partners choose to expose each other to their bodily fluids, usually after getting checked for sexually transmitted diseases.

"I'm going to be up front about it... that I don't get into the (dental) dam situation, I don't want to use one and I don't want to have one used, so we just don't do that. Unless it turns into a relationship and things progress, and then you can start talking about being fluid bonded and make sure, that way later on in the relationship you trust your partner to honor that. But you know, but I'm going to be up front and say it's safe sex or no sex, period."

"I can't deal with the (dental) dam situation, so I won't go there with somebody unless I'm fluid bonded with them. I find that my kind of range of sexual behavior is very, very limited when it comes to casual sex because I won't do things that would require certain things that I'm not comfortable using. So it's like these activities are okay, and from there the risk factor goes up and I can't go there with you. But I will go there with a partner that I'm fluid bonded with."

Some participants spoke about the denial of risk.

"Even though they are male to females, there's still that male bravado there that okay, this can't happen to me..."

"So among the transsexual community, I believe that the HIV/STD rate is increasing because the Latino community is in fact still thinking that it cannot happen to them."

Other participants linked discrimination and low self esteem with substance abuse and specific HIV risk behaviors.

"The whole fact of feeling discriminated against will stretch you out, will put you in a certain mood of low self esteem, and will cause you to sometimes abuse drugs or alcohol, which leads to unprotected sex, or sharing needles, or anything of that nature."

"What contributes to a higher rate in transsexuals or in gays is once again, discrimination... which leads to drugs (and) alcohol abuse, which leads to unprotected sex."

Needle sharing among IDU sex workers was mentioned by several transgender women participants.

"Well, street drugs... mainly it's just the use of needles, intravenous injections and sometimes people just aren't real careful."

One participant mentioned needle sharing as the way she became HIV-infected.

"When I was I7 and first came out here to Virginia, I shared needles with somebody who was HIV positive – that's how I contracted it. (I didn't clean needles) then, and I don't know why I didn't. I didn't think."

The need for more prevention education was expressed by many participants, but especially by the Latina transgender women in northern Virginia. Some of them mentioned the need to break down the cultural barriers that prevent condom use. Other Latina participants reported some specific unmet needs such as HIV education workshops, condom distribution by outreach workers, HIV counseling and testing, and individual and group level interventions.

"They have to go to DC, because here in Virginia, we don't have any groups, we don't have any support groups, we don't have any type of educational program of any sort that would help educate the transgender Latino community, or any community for that matter."

"If the state (could) give us something here in Virginia, where we will be able to have focus meetings, where they will be able to educate them about HIV, about different kinds of stuff, it would be easier... Having something here in the Virginia area, where we will be able to just walk or take the bus, instead of traveling to Washington or traveling to Maryland."

Participants also identified FTMs and transgender youth as groups with unmet needs for prevention education. Although only a few of the participants mentioned attending an HIV prevention workshop specifically for transgender people, many knew of the educational work of various AIDS service organizations in Virginia and DC. Some also learned about HIV prevention through their transgender support groups or friends, and several participants were or had been HIV educators and outreach workers. Some participants had seen HIV prevention posters and flyers in clubs, and still others mentioned their doctors or the internet as information resources. Condom distribution by outreach workers was reported, specifically in Richmond, Norfolk, Northern Virginia and Washington, DC.

"I see now you have the sense that now the community outreach is trying to come out and touch base with the transgender girls. (They) even come out into the streets, into the clubs, to different functions, (to) provide condoms and stuff to protect themselves."

"We have a small army in this area, particularly the Fan, that I personally go out on a bicycle with a backpack full of condoms... Everybody here is very good about helping anybody with anything that prevents it."

However, some participants felt the state was not doing enough to prevent HIV transmission among transgender people, and they had some specific suggestions.

"You have to create groups in which they can come and talk to people, HIV/STD educators who will answer your questions, who will teach you how to protect yourself and educate yourself and preventing these diseases... Virginia needs to do more than just advertisements and flyers at a club, churches, or wherever you can find them at. We need focus groups, we need funding to pay educators to bring the community together and teach them on a one-to-one basis."

"The whole needle exchange programs are essential, particularly for trans people who are maybe using injections that maybe have access to clean needles."

"I think the level of employment is really a high prevention factor. If you don't have to work on the street for some reason, you're not that at risk, and then you're not one of those (at risk)."

Some participants felt there was a need for more cultural competency training for providers of HIV prevention education and HIV treatment, which would do more to create a comfortable, welcoming atmosphere for them.

"I think it would be great if the state can create programs for transgender people where they will feel comfortable and not be discriminated against by the organization."

"A transsexual will feel more comfortable knowing that they're accepted in whatever organization they go into. If they're focusing on transsexuals, you will feel more comfortable, more open to answer or ask questions."

### **HIV** Testing

Barriers to getting tested reported by the participants included not knowing where to get tested, fear of hostile or insensitive HIV CTR (counseling, testing and referral) counselors, and fear of being HIV positive. Fears of testing positive, and perceptions of the negative consequences, were commonly expressed.

"It's always scary to go get tested. And it's scarier that you know that society is going to treat you different if they were to know of your HIV status... I'm not so much afraid of the disease because we all have to die of something... If I was HIV positive, I would be more afraid of the way society or my peers would treat me than the disease itself. So of course that's why it's always fearful to me."

Fears of even more discrimination were a barrier for some participants.

"It's already hard for them because society is discriminating (against) you... that imagine if you were HIV positive, what more discrimination would come upon you by them knowing that you are that?"

Some participants mentioned that due to their overt status as transgender people, going to get tested was more difficult for them than gay men.

"Gay men are more successful at going into a clinic and being treated fairly, because (they are) not necessarily seen that they're gay. But transgender people going into a clinic, we have qualms about going to the clinic as far as the way that we're treated."

The most common barrier expressed by many participants was the fear of not being able to keep their test results private.

"The fact that you go there and you're not sure you're going to receive an anonymous test, or you're not sure that this is going to stay (between) you and your counselor, then you're afraid to go get tested because you don't want anyone else to know your status. That's what makes them afraid."

"They're scared somebody may find out, (and) they don't want nobody to know their business. They think (if) they go to the doctor, everybody's going to know, and they're going to be ostracized and all that."

Fears of disclosure of getting tested were especially true for participants in rural areas, towns and small cities. Some felt they could not trust their local health departments.

"I think a lot of it is gossip too. When you go get tested and a lot of people talk about you after your results come back. Because it does leak out.... People in the health department gossip and that's why a lot of people don't want to get tested at the health department."

"When I found out I had it, it was out quick, and I didn't tell nobody. How could anybody know that? Somebody in the health department had to have said something."

The Latina participants again mentioned the lack of specific resources for them.

"Because we don't have any organizations here in Virginia, we won't be able to recommend transgenders to do it here... All of them have to travel to DC or Maryland in order for them to get tested. There are organizations (there) that will be able to take care of transgenders. Here, there's only hospitals and clinics. If we recommend (that) somebody (go) there, they will just look at you like (you) are crazy or strange."

"The fact (is) that they don't have any place where they can go and get tested and get treated (for) the disease or their HIV status. They don't know that they are able to get on medication and continue living their lives as normal. I think that has a lot to do with them.

Some participants had no issues with testing and got tested regularly. Incentives for getting tested included wanting to know their status and qualifying for sex reassignment surgeries. Due to their concerns about privacy, however, only a few participants recommended their local health departments as places to get tested. Most participants recommended either going to a private physician or to AIDS service organizations in Washington, DC, for the security of anonymous testing.

"There's a certain anonymity to the urban environment that you can just go and get yourself tested, and you're not seeing the local doctor or asking anybody in a smaller community or a more personally oriented community."

"Basically, if you're going out and getting tested for HIV all the time, you maybe are doing something that's like putting you at risk for getting it. Otherwise you wouldn't need to be getting tested all the time. So I always try to get it done anonymously. I do it (in DC) usually, just because they have the 20 minute ones and I just wait for it."

Some participants mentioned the importance of having a safe space for testing to lessen the accumulation of fears around testing.

"If you are in an unsafe surrounding, you're less likely to go to a doctor because you do not only fear the doctor and the other people around you talking about you. You also have the fear of being fired from your job, (and) you have the fear of having no privacy at all."

"(If) people are feeling more comfortable and safe, and (the same counselor) is going to see them and repeat it, (someone) who is very responsible, very discreet, and most of the girls give such good feedback about the clinic... I think they could mostly come here and be very comfortable."

One Latina participant recommended a specific program targeting her population that would include education on the need to get tested.

"I would try to create a program to make all those people who have never been tested to actually come and get tested because there (are) a lot of people who, because of their lack of knowledge on the HIV virus or the STDs, they don't want to get tested. So we have to create programs in which you educate them, but not only educate them, you have to educate them on getting tested."

## Improving Access to HIV/AIDS Treatment Services

The participants had many suggestions about how the state and local organizations might improve HIV-related service delivery to transgender people. Some participants suggested new organizations and funding to improve services.

"We need to focus on the transsexual group because there are enough funds, groups, (and) organizations helping heterosexuals...gay, lesbians, and bisexuals. But there (are) not enough organizations focusing or targeting the transsexual community in general. That's what Virginia needs to provide – funds to help create organizations, groups that will make the transsexual community feel comfortable..."

Many participants had issues with social service providers who treated them poorly.

"I believe that social services probably needs to be educated about the population, (you need people who are) open and willing to deal with transgenders to make them feel more comfortable and give them all the opportunities that they're entitled to without judgment."

"I think maybe case managers or social workers who are more caring, and who have (compassion). I've had clients who tell me that case workers and social workers have told them that they got what they deserved because of the lifestyle that they lived."

Some participants thought that more sensitivity and awareness training was needed for doctors, social workers and other staff to improve their service relationships with them.

"I think... that social worker, that doctor, it's not that they want to make you feel uncomfortable. They just don't know how to make you feel comfortable... This needs to be included in diversity training..."

"The HIV care workers, people who visit in people's homes, just getting them used to dealing with transsexual people. So educating them on how to deal properly with somebody who is transsexual, making sure they use the right pronouns, that sort of thing."

Many felt their medical providers needed more technical training about transgender people and transgender care service delivery.

"The doctors, they need to be educated... (about) some of the transgender concerns, the care, the side effect of certain treatments..."

Some participants felt that their difficulties were not just with HIV-related medical services but all medical services.

"Making going to the doctor not an issue...I know many more trans people who won't go to the doctor because they're trans than I know people who won't seek out healthcare in general. You

have bad experiences, or you hear of people with bad experiences, or you don't want to come out every single place you go to every single person... So people just don't go to the doctor."

The solution for some was transgender staff or even a transgender-specific HIV clinic.

"When we walk into a place... we feel alienated and feel shunned from the beginning, because typically they don't understand what we're all about. So they can't service us wholly... Just having somebody there (who is) transgender to speak to us, on staff, that we could connect with and really open up to, I think would make it better for services."

"You might (even) have gay people on staff, but there's a lot of gay people that still don't understand what we do. So I think that's a very good point. I think if they incorporate more transgender people when we're coming into a place to be tested or whatever, and you see another girl there, it's just 'hey girl.'"

"I think one of the things that would really help the trans community would be a very, very trans-specific clinic that was open for the trans community all the time."

One participant suggested a state intervention program that would address low self esteem and substance abuse.

"It's a shame that in the state of Virginia, we don't have some sort of program or group or meeting of some sort that enables us to be able to work together as a group or as individuals who are trying to transgender... (to help) us with our self esteem or educating us or giving us some sort of advice within each other within our transgender community, so we can build up our self esteem. By the state doing that, I think it would help to reduce the amount of substance abuse, whether it be with drugs or alcohol."

Still other participants saw job training and vocational rehabilitation for transgender people to be a priority.

"I believe there need to be more training programs that are available for our community because I think that because we have so many poorly educated transgender person out there, I think that we should offer more educational services for that population, as well as services to help them just to build a resume, because some people don't even know how to structure a resume to be able to even go out and get a job... Someone should assist them in getting job placement."

One participant living in a rural area spoke about the need for a comprehensive program she accessed in Florida.

"(They) had this HIV place where you go and they help you, and if you need help with your bills, or if you need help with your medicine, or anything like that, but they don't have anything like that here... I think they should set up a program (like that) here, a place (that's) a food bank, (where) you can get food once a month if you need it, counseling, condoms, classes... education about if you do have it, how to deal with it, if you have a partner and how not to give it to that partner."

Another participant saw the need to extend treatment services to the incarcerated.

"The treatment would go into the jails and treat the trans and the people who are HIV positive in the cells, because they take you to certain parts of the jail, put you in a cell, and they don't

come in. You get shorted on your treatment and your medication you should have... A lot of the girls have been down to Richmond City Jail and died because of the way they were treated with their diet... You have to have a full meal to take your medicine in the mornings, and I have never seen a jail have a full meal on any tray they ever gave a person, much less someone who is dying and trying to keep the medication in."

Those in the Roanoke focus group expressed a great need for services, but they also were somewhat pessimistic about getting them.

"I think in the city of Roanoke alone, there should be more programs set up for the HIV community... because once your job finds out that you're HIV positive, you lose your job a lot of times, then you lose your home because you don't have the money to pay for it. So there should be programs, just like the welfare system, there should be something set up where these people can get the help and support financially not only physically and spiritually and mentally..."

"I had a friend who had to go outside the state when they found out they were HIV positive... they had to learn to live with it, and they had to go to Los Angeles to get the support and the drive that they needed... There (should) be a program in the City of Roanoke where if you're HIV positive, you can sit down with a person one on one and share with that person your fears, and your nightmares, and ask them what can I do to make my everyday life and my routine better. There's nothing here in the City of Roanoke, there's a lot of prejudice toward the HIV community here."

Many participants talked about their difficulties covering the costs of their HIV treatment. Some had exhausted their insurance benefits and others lost coverage.

"With more funding, we would be able to provide... a better program which will extend more benefits, because the benefits are limited. I know of health insurances that will not cover your HIV treatment medicine. So you have to go through organizations that will help you with that. But in Virginia, there is not enough funds or enough money to cover those treatments."

"People who are HIV positive, if they check off HIV, you're denied your health insurance. And that's wrong. HIV is not really your death sentence – you can die from anything... Once your health insurance finds out that you're HIV positive, that's a door shut in your face... There (should) be some kind of program set up where HIV positive people and transgender people can get the insurance benefits just like a heterosexual person that may have cancer or diabetes can get, and not (at) high cost."

A Latina participant spoke of being classified as a gay male in order to be eligible for HIV/AIDS services.

"There are no funds specifically for the transgender Latino community, so a lot of people would have to be put into another group, considered a gay male, or a feminine gay male, or some sort of, there is not something specific for the transgender Latino community."

## **Summary of Key Findings**

Social stigma, discrimination and victimization are constants in the lives of the transgender people who participated in these focus groups. Access to transgender care services – principally hormone therapy – was a priority need for most of the participants, since it allowed many to pass in their chosen genders, avoiding discrimination and victimization associated with the social stigma. However, many participants experienced barriers to its access, including a lack of insurance, identity documentation issues and the lack of willing providers. The lack of insurance itself was often related to a lack of employment in connection with discrimination, or sex work as an alternative means of earning income. Those with insurance had either no or limited coverage of the costs of their transgender care. Due to these insurance problems and the lack of providers, self-medication of hormones and injection silicone use were frequently mentioned by participants, both of which involve their own health risks. Although not specifically mentioned by participants, sharing of needles to inject hormones and silicone also carries viral transmission risks of HIV and Hepatitis B and C.

Some participants mentioned hostility, insensitivity, disrespect and even discrimination by medical providers as barriers to accessing regular medical care. Some participants had negative experiences with insensitive or hostile doctors, especially female-to-male participants when trying to access gynecological care. Fears of negative reactions caused some participants not to disclose their transgender status, and to avoid medical care when necessary. Fewer participants were out to their doctors, but they enjoyed comfortable relationships with them, staying with the same doctor over time. Lack of insurance, connected with a lack of employment, was also a barrier to access, as were identity documentation problems.

The participants expressed mixed attitudes about mental health care. Those who had negative experiences with their psychotherapists were treated very poorly, due to either a lack of experience with transgender people, or a belief that transgenderism is a mental illness. Many who chose not to access mental health care had very negative attitudes towards it, due to traditional mental illness stigma and their feelings that being transgender was not a mental illness. Those seeking psychotherapy had great difficulties finding mental health providers who were compassionate, experienced and competent.

Many participants had experienced employment discrimination and difficulties in employment, including job loss and failures to be hired. A non-passing physical appearance was often linked to job discrimination and difficulties with co-workers. Hostile work environments, with harassment and sometimes physical abuse by co-workers, were reported by many participants. Generally, those in white collar positions, with employment longevity and/or who were good at their jobs, were more fortunate in keeping their jobs when they came out as transgender. Housing discrimination was experienced by

fewer participants than employment discrimination, with common barriers of employment difficulties and the stigma associated with being transgender or transsexual. Some African-American and Latina transgender women mentioned discrimination in public housing and shelters.

Many participants were survivors of violence, with murders of peers often reported. African-American transgender women sex workers experienced the most violence. Many participants also spoke of harassment and intimidation in their own neighborhoods. Some complained about secondary victimization by the police when they reported the violence, and others reported discrimination by the police, including being blamed for their own assaults.

High levels of substance abuse were reported by participants, with alcohol and marijuana use most commonly mentioned. Many of the individual reasons given by participants for drinking and drugging could be summed up as the need to cope with the many interrelated life stressors of being a member of a socially marginalized, heavily stigmatized sexual minority. Other reasons included coping with depression and internalized transphobia. Several participants also mentioned using drugs as a means of coping with the pressures of sex work, and peer pressure.

Some participants also spoke about how gender transition eased their depression and reduced their substance abuse. Passing in their chosen genders during or after gender transition was the most significant means of improving self-esteem for many participants, especially for most of the transgender women. Passing allowed them to avoid the social stigma, affording the societal acceptance previously missing in their lives, as well as the means to lead a normal life. Passing was also important for the self-esteem of the FTMs, yet some were ambivalent about being perceived as non-transgender men.

Having sex was another means of improving self-esteem, since it also included affirmation of gender identities for many participants. Most of the African-American and Latina transgender women felt their gender identities were affirmed by having sex with non-transgender men. Gender identity affirmation through having sex with non-transgender women and men was also expressed by some but not all of the FTM participants. The sexual orientations reported by the participants should be viewed with secondary importance over their sexual behaviors, because labeling them might not be accurate nor imply sexual risks. Transgender people in gender transition also question and experiment with their sexualities, and changes in sexual orientation are commonplace.

Despite high levels of HIV knowledge among participants, many still engaged in unprotected sex. Transgender women had unprotected sex with non-transgender men, and FTMs had unprotected sex with non-transgender men, non-transgender women and other FTMs. Other risk factors included substance abuse and unprotected sex in prostitution due to extreme financial need. Sex workers were mostly transgender women, but there were also some FTMs who did sex work. Reasons for sex work included lack of regular employment, economic vulnerability and a fast, easy means to earn income.

Perception of HIV risk greatly varied and was highest among African-American transgender women, who also had the highest frequency of condom use. The lowest level of condom use seemed to be among Latina transgender and transsexual women. Reasons given for not using condoms or other barriers included monogamy, denial, substance abuse, fluid bonding and cultural and societal factors. Needle sharing among IDU sex workers was mentioned by several transgender women participants.

Barriers to getting tested for HIV included not knowing where to get tested, fear of hostile or insensitive HIV CTR counselors, fear of doctors and needles, and fear of testing positive and its consequences. The most common barrier expressed by many participants was the fear of being unable to keep their test results private, especially for participants in rural areas, with some participants unable to trust their local health departments. As a consequence, many participants recommended either going to a private physician for testing or to AIDS services organizations in Washington, DC, for the security of anonymous testing.

Latina participants were particularly vocal in expressing many unmet prevention education needs for them, including HIV education workshops, condom distribution by outreach workers, HIV counseling and testing, and individual and group level interventions. Other groups with unmet needs for prevention education identified by participants were FTMs and transgender youth. Many participants thought additional cultural competency training for doctors, social workers, prevention education and HIV care providers was necessary. Many also felt that medical providers needed more training in transgender care service delivery. Some participants felt that their difficulties were not just with HIV-related medical services but all medical services, and some suggested hiring transgender staff, or even starting a transgender-specific clinic. Other participants viewed education and job training for transgender people to be a priority, to give sex workers an alternative means of earning income. Many participants also felt the need for financial assistance to cover the costs of their HIV treatment.

#### Recommendations to VDH and the VHCPC

This population faces a multiplicity of interrelated risks that must be dealt with holistically. Multi-level interventions are needed to improve the response of Virginia's public health system, increasing the likelihood that transgender persons will receive appropriate healthcare that will lower these risks. However, the participants of these focus groups identified many broken relationships with medical, mental health and social service providers that must first be addressed before other steps can be taken.

Demand for access to transgender care – principally hormonal therapy – was very high and offers potential as a risk reduction method. The General Theory of Risk Reduction in Transgender

Populations<sup>4</sup> is based upon the simple premise that people who are happier in their bodies tend to take better care of them. Affording transgender people a medically safe means of transforming their bodies would improve their self-esteem and bodily comfort, producing bodies worth protecting. Possible results of the application of this theory would include a lower likelihood of engaging in self medication of hormones, injection silicone use and substance abuse, and a greater likelihood of practicing safer sex.

Study results support the following recommendations for consideration by VDH and VHCPC. Successful implementation of some of these recommendations would require high levels of cooperation between state and local agencies.

- I. Cultural competency training for medical, social service, shelter and transitional housing staffs. This training would be focused on raising sensitivity and awareness to the needs, issues and concerns of transgender people at risk, with an emphasis on creating safe spaces for them.
- 2. Medical service delivery training for medical providers in transgender care services. This training would inform doctors, nurse practitioners, physician assistants and nurses about transgender hormonal therapy: patient expectations, its risks, contraindications, adverse reactions, and drug interactions. It would also stress the importance of providing sensitive gynecological care to FTMs.
- 3. **Training for mental health providers**. This training would emphasize the need to treat the mental health needs of transgender people in a non-stigmatizing, non-judgmental way.
- 4. Local clinical transgender care programs operating on a harm reduction model. With transgender hormonal therapy as a magnet, transgender patients could be screened for HIV and other STDs. An organizational environment that attracts transgender persons through trans-specific health services may facilitate awareness and assessment of other chronic illnesses, while providing sensitive and appropriate wellness care. Hiring and training transgender staff members would facilitate a welcoming environment.
- 5. A vocational rehabilitation program for transgender sex workers. Many of the participants' problems stemmed from a lack of employment opportunities. A pilot program with a state or local agency to give transgender sex workers an alternative to working the streets should be implemented.
- 6. Expansion of outreach and condom distribution to transgender subpopulations, especially Latinas, commercial sex workers, youth and FTMs. Ideally, transgender people from these subgroups should be hired and trained to provide culturally appropriate prevention education and condom distribution in their respective locales. Since many transgender people usually frequent their

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<sup>&</sup>lt;sup>4</sup> The General Theory of Risk Reduction is attributable to Ben Singer (in Xavier et al, 2005).

support groups and providers, these new programs might differ from traditional street and venue-based outreach in their efforts to connect with these often hard-to-reach groups.

- 7. Developing transgender-specific HIV/AIDS prevention materials and implementation of transgender-specific prevention workshops. As with other populations, materials must be culturally-appropriate and sensitive to transgender populations if they are to be effective. Program evaluation is also required to assess the effectiveness of these new materials and workshops.
- 8. Educational programs for transgender people about transgender care. Given the popularity of injection silicone use by many participants, it is likely that they do not completely understand their risks and medical alternatives that might be available to them.
- 9. **Improvement of HIV testing for transgender people.** The concerns expressed by many participants over the lack of confidentiality when they are tested must be addressed, in order to provide HIV treatment and implement secondary prevention for those who test positive.

## References

Bockting WO, Robinson BE, Rosser BRS. (1998). Transgender HIV prevention: A qualitative needs assessment. AIDS Care, 10(4), 505-526.

Boles J, Elifson K. (1994). The social organization of transvestite prostitution and AIDS. Social Science and Medicine, 39: 85-93.

Clements K, Katz M, Marx R. (1999). The Transgender Community Health Project: Descriptive Results. San Francisco Department of Public Health. Available online at http://hivinsite.ucsf.edu/InSite.jsp?doc=2098.461e

Clements K, Wilkinson W, Kitano K, Marx R. (1999). HIV Prevention and Health Service Needs of the Transgender Community in San Francisco. *International Journal of Transgenderism*, 3, 1&2. Available online at http://www.symposion.com/ijt/hiv risk/clements.htm

Clements-Nolle K, Marx R, Guzman R, Katz M. (2001). HIV prevalence, risk behaviors, health care use, and mental health status of transgender persons: Implications for public health intervention. *American Journal of Public Health*, 91(6), 915-921.

Elifson K, Boles J, Posey E, Sweat M, Darrow W, & Elsea, W. (1993). Male Transvestite Prostitutes and HIV Risk. American Journal of Public Health, 83(2) 260-262.

Hendricks M, Bradford J, Xavier J. (2004) The Virginia Transgender Health Initiative: Assessing Needs (Symposium), the 2004 American Psychological Association Annual Convention, Honolulu, HI.

JSI Research and Training Institute, Inc., and GLBT Health Access Project. (2000). Access to Health Care for Transgendered Persons in Greater Boston, July 2000. Available online at: http://www.glbthealth.org/documents/transaccessstudy.pdf

Kammerer N, Mason T, Connors M, Durkee R. (1999). Transgender Health and Social Service Needs in the Context of HIV Risk. *International Journal of Transgenderism* 3 (1+2). Available online at: http://www.symposion.com/ijt/hiv\_risk/kammerer.htm

Kenagy G. (2002). HIV among transgender people. AIDS Care, 14 (1), 127-134.

Kenagy G, Bostwick W. (2001). Health and social service needs of transgendered people in Chicago. Chicago: Jane Addams College of Social Work, University of Illinois at Chicago.

McGowan CK. (1999). Transgender Needs Assessment. New York: The HIV Prevention Planning Unit of the New York City Department of Health.

Nemoto T, Operario D, Keatley J, Han L, Soma T. (2004). HIV Risk Behaviors Among Male-to-Female Transgender Persons of Color in San Francisco. *American Journal of Public Health*, 94,(7), 1193-1199.

Nemoto T, Operario D, Keatley J, Villegas D. (2004). Social context of HIV risk behaviors among Maleto-Female Transgender Persons of Colour. *AIDS Care*, 16(6), 724-735.

Reback C, Simon P, Bemis C, Gatson B. (2001). The Los Angeles Transgender Health Study: Community Report. Los Angeles: University of California at Los Angeles.

Rodríquez-Madera S, Toro-Alfonso J. (2000, October). An exploratory study regarding social vulnerability, high risk sex conduct, and HIV/AIDS in Puerto Rico's transgender community. Roundtable presentation at the 2000 United States Conference on AIDS, Atlanta, GA

Simon P, Reback C, Bemis C. (2000). HIV prevalence and incidence among male-to-female transsexuals receiving HIV prevention services in Los Angeles County. *Journal of Acquired Immune Deficiency Syndrome*, 14(18), 2953-2955.

Xavier J, Bobbin M, Singer B, Budd E. (2005). A Needs Assessment of Transgendered People of Color Living in Washington, DC. *International Journal of Transgenderism*, 8 (2/3), 31-47.

# Appendix I: Glossary of Transgender Terminology

Crossdresser: Someone who wears the clothing of the other sex, formerly called a transvestite. It usually refers to a man who crossdresses, but there also are women who crossdress.

Drag Queens/Drag Kings: performers who crossdress to perform the art of female and male illusion, often in highly competitive shows. Drag performers are usually gay men or lesbians, and while some consider themselves to be transgender, many do not.

Female-to-Males, FTMs, F2Ms: transgender persons born into female bodies with non-female gender identities and/or gender expressions. Some FTMs identify themselves as transgender men, transsexual men or transmen, but many others resent being perceived as non-transgender men, whom they regard as sexist oppressors.

Gender: a psychosocial construct used to classify a person as male, female, both or neither. Although gender and sex are commonly used interchangeably by most people, gender is very distinct from sex.

Gender Dysphoria: intense, persistent feelings of anguish resulting from the inappropriateness of one's birth sex, or from being forced to conform to rigid gender norms based upon one's birth sex.

Gender Identity: someone's personal sense of being a man or a woman, or a boy or a girl, or for some transgender people, something entirely unique. Gender identity is commonly communicated to other people by means of one's Gender Expression.

Gender Identity Disorder: a controversial classification in the *Diagnostic and Statistical Manual of Mental Disorders*, published by the American Psychiatric Association. GID is used to treat transgender persons but it also stigmatizes them, since it regards their gender variance as a psychopathology.

Gender Queer: a self-identification term embraced by many transgender youth, who totally reject the gender binary system and do not use the gender vector terms (FTM/MTF) to identify themselves.

Gender Transition (or simply, Transition): the period when transsexual and transgender persons begin living in the gender congruent with their gender identities.

Injection Silicone Use (ISU): receiving or self-administering unencapsulated injections of silicone or other heavy oils in the cheeks, breasts, chests, hips and buttocks to modify the body to resemble that of the other sex. Banned by the U.S. Food and Drug Administration in the 1960s, ISU involves immediate viral and bacterial transmission risks, and later serious systemic health risks, including disfigurement and even death from multiple complications. ISU is viewed as a fast, cheap alternative or adjunct to transgender hormonal therapy that preserves sexual virility in MTFs. While ISU is very popular among Latina and African-American transgender women, there are also reports of FTM ISU in the drag ball cultures along the eastern coast of the U.S., as well as ISU in HIV positive non-transgender men to conceal HIV wasting syndrome.

Intersex: the preferred term for hermaphroditic, pseudo-hermaphroditic and other persons born with non-standard bodies, which may include ambiguous genitalia and/or chromosomal anomalies. Many intersex infants and children have their ambiguous genitalia surgically "normalized" without their consent, which results in loss of sexual response in adulthood. Some intersex infants are also sexually reassigned without their consent, and like transgender persons, must deal with gender identity issues later in their lives.

Male-to-females, MTFs, M2Fs: transgender persons born into male bodies with female gender identities and/or gender expressions. MTFs may also identify themselves as transgender, transgender women, transsexual women or transwomen.

Passing: a common goal of most transgender persons, passing is successfully altering one's gender expression to resemble that of the opposite sex.

Sex: the anatomy and biology that determines whether a person is male, female or intersex.

Sex Reassignment: hormonal and surgical modification of the body to make it as much as possible like that of the other sex, in order to facilitate living in the social role congruent with one's gender identity.

Sex Reassignment Surgery (SRS): the permanent surgical refashioning of genitalia in MTFs and FTMs, and the removal of the breasts in FTMs, to achieve congruency between somatic status and gender identity.

Standards of Care: a set of guidelines formulated by the Harry Benjamin International Gender Dysphoria Association, now in its sixth version. The Benjamin Standards were originally intended to safeguard both transsexual persons and their service providers (endocrinologists, surgeons and psychotherapists) by imposing various requirements. However, the Benjamin Standards today are controversial, and many transsexual persons regard them as a gatekeeper system that restricts access to sex reassignment services.

Sexual Orientation: an individual's romantic and physical attraction to members of the same, opposite or either sex. An individual may be heterosexual, homosexual, lesbian, bisexual, or asexual.

Transgender: an umbrella term used to describe gender variant people, who have identities, expressions or behaviors not traditionally associated with their physical sex or their birth sex. It is preferred by most transgender people over the clinical terms transvestite and transsexual, which do not accurately describe all transgender people and also have a clinical, stigmatizing connotation. Transgender is commonly mistaken to mean transsexual, and it is important to note that most transgender people do not wish to change their sexual anatomy.

Transgender Care: also called Trans Health, it includes transgender-specific medical procedures, such as Transgender Hormonal Therapy and Sex Reassignment Surgeries, various cosmetic procedures, psychotherapy, and speech therapy. Most transgender care is not covered by health insurance.

Transgender Hormonal Therapy: the medical administration of estrogens (for male to female transsexuals) or androgens (for female to male transsexuals) to affect the development of secondary sexual characteristics of the other (non-birth) sex.

Transphobia: hatred of transgender people, manifested by acts of discrimination, harassment, and violence, including murder. Transphobia also creates multiple barriers to access to all types of medical care. It differs from homophobia in that it carries an implicit justification: that by "flaunting" their feminine or masculine appearances – i.e., by being themselves – transgender people are simply asking for it. Internalized transphobia, a profound unhappiness with being transgender, is similar to internalized homophobia, and manifests as depression, suicidal ideation, substance abuse and sexual risk taking.

Transsexual: persons who are profoundly unhappy with their birth sex, and who seek to change or have already changed their body to be congruent with their gender identity. Transsexual usually implies access to sex reassignment surgery, and thus transsexual persons have the highest level of need for access to transgender care services among all transgender persons.

# Appendix II: HIV Community Planning in Virginia

#### Historical Overview

In 1994 the Centers for Disease Control and Prevention (CDC) changed the manner in which federally–funded state and local HIV prevention programs would be planned and implemented. State, territorial and local health departments receiving HIV prevention funds through the CDC were asked to share with representatives of affected communities and other technical experts, the responsibility to develop a comprehensive HIV prevention plan using a process called HIV Prevention Community Planning. The basic intent of the process was to increase community involvement, improve the scientific basis of program decisions, and target resources to those communities at highest risk for HIV transmission. Although the CDC had two primary components embedded within the process – targeting populations for which HIV prevention activities will have the greatest impact and reducing HIV transmission in populations with highest incidence, state and local jurisdictions were encouraged to prioritize prevention needs as indicated by their own epidemiological data. HIV Community Planning Groups (CPGs) were to be developed and would work in conjunction with public health agencies to carry out this process.

HIV Prevention Community Planning had three major goals that provided the overall direction for community planning: (I) supporting broad-based community participation, (2) identifying and prioritizing needs and interventions, and (3) ensuring that available resources were used to address the needs of the targeted populations and interventions. Jurisdictions were required to create and maintain at least one CPG that met the goals, objectives, and operating principles set forth by the CDC. If there were more than one community planning group in a jurisdiction, the health department would be responsible for deciding how best to integrate cross-jurisdictional community planning. If there were multiple jurisdictions within a state, state and local CPGs were expected to have ready access to and review each other's comprehensive plans. CDC has maintained its commitment to the concept of HIV prevention community planning and monitors the progress health departments and CPGs are making in meeting these expectations.

## VHCPC Structure and Operations

While the CDC mandated that HIV Community Planning Groups be developed, it left the design of those groups to the individual states and territories. Virginia is one of a growing number of states that have one statewide planning body, while other states opt for regional planning bodies reporting to a

<sup>&</sup>lt;sup>5</sup> National Center for HIV, STD and TB Prevention: Division of HIV/AIDS Prevention. HIV Prevention Community Planning – GUIDANCE.

statewide planning committee or to have multiple planning committees within the state based on regions. Virginia opted for one statewide planning group with representation from each of the five regional health planning districts across the Commonwealth. The Virginia HIV Community Planning Committee (VHCPC) is composed of education and service providers, clients, state agency representatives, clergy, and private citizens who work cooperatively with VDH to develop an annual plan for comprehensive HIV prevention and to advise VDH on its implementation. The Committee is led by an elected community co-chair and an appointed Virginia Department of Health co-chair. Representation also mirrors the HIV epidemic within these regional districts. The VHCPC as described in its bylaws must be comprised of no less than 25 and no more than 35 members. Members are selected from a pool of nominees to represent the population of HIV-positive Virginians in terms of age, race, sex, sexual orientation, HIV risk, geographic locality, and professional expertise. The VHCPC has four subcommittees, for research, standards and practices, Ryan White, and STDs.

The research subcommittee was established at initiation of the VHCPC and is responsible for establishing and monitoring the research and evaluation agenda. Target populations are identified and thoroughly discussed before being brought to the consideration of the full committee. The standards and practices subcommittee is responsible for developing minimum standards, based on established best practices that contractors must meet in order to receive VDH funding for prevention interventions. In September of 1995 the VHCPC was asked by VDH, in concurrence with a request from the CDC, to expand their activities to include planning for Ryan White Care funds and STD prevention. Since the VHCPC already utilized data derived from Ryan White Care and STD reporting to develop the comprehensive plan, it was logical to enhance the Committee's mission specifically to address these issues.

Role of the Survey and Evaluation Research Laboratory and the Community Health Research Initiative

The Survey and Evaluation Research Laboratory (SERL), the applied research division of Virginia Commonwealth University's Center for Public Policy, has been a partner with VDH since the initiation of its HIV/AIDS response in the late 1980s. SERL staff conducted the first Knowledge, Attitude, Belief and Behavior (KABB) surveys in Virginia; wrote the proposal for and continue to administer the Central Virginia HIV Care Consortium (funded by RWCA Title II); assisted HRSA in the design of the RWCA Title II data reporting system; and continues to capture and report a variety of care and prevention data to HRSA, CDC and to VDH. When HIV Community Planning was first funded in 1994, SERL began what is now over a decade of collaboration with the VHCPC. In part due to the extensive HIV research and technical assistance programs in SERL, the community health emphasis in SERL had grown steadily over the past decade. Effective September 2005, this component of SERL's work was established as the

Community Health Research Initiative (CHRI), an independent department with the new L. Douglas Wilder School for Government and Public Affairs. CHRI and SERL are closely linked, with SERL's data management and survey divisions continuing to provide ongoing support for CHRI projects.

SERL/CHRI staff have designed and implemented more than 40 research and evaluation projects sponsored through the VDH by HRSA and/or CDC, and continue to work closely with VDH and the CPG to integrate related efforts wherever possible, in order to enhance the efficiency and effectiveness of Virginia's overall response to HIV/AIDS. Thus, when community planning activities were initiated in 1994, Virginia already had an applied social science research partner fully integrated into the process. SERL/CHRI's annual work plan is developed in conjunction with members of the research subcommittee, who have a special responsibility to monitor SERL/CHRI's performance. Specifically on behalf of the VHCPC, SERL/CHRI has conducted extensive literature review and bibliographic research to provide population profiles and sub-population intervention best practices to assist with prioritization. SERL/CHRI staff members conduct quantitative and qualitative studies to gather population-based data for prevention planning and implement evaluation studies to assess the readiness of funded contractors to carry out effective programming. VDH, the VHCPC, and SERL forged a relationship that has helped to build an infrastructure to support effective community planning. From the beginning of the research collaboration, all entities recognized the need to involve affected populations and health care providers in the planning process. This direction will receive increased emphasis with emergence of the Community Health Research Initiative.

VHCPC/CHRI research studies typically happen over a period of I-3 years and in a sequential manner. Literature review and careful discussion are used to assess the sufficiency of available data to support HIV prevention planning and to provide a foundation for primary research deemed necessary and/or desirable prior to new program initiatives.

# Appendix III:

# Virginia Transgender Health Initiative Study Focus Group Questions

#### 1. ACCESS TO REGULAR MEDICAL SERVICES

• Getting good health care can be hard for us, due to discrimination, lack of doctors who understand our needs, and lack of health insurance coverage.

What have you heard from transgender people you know about getting health care?

PROMPT: Are you comfortable telling your doctor you're transgender?

PROMPT: Is health insurance an issue among transgender people you know?

#### 2. ACCESS TO TRANSGENDER CARE SERVICES

• Many transgender people often have trouble getting hormone therapy or mental health care.

Do transgender people you know have these difficulties?

Do you know anyone who has received hormones from someone other than a doctor or licensed health care provider?

PROMPT: Do you know anyone who has gotten silicone injections instead?

IF HORMONE OF SILICONE INJECTION USE MENTIONED, PROMPT:

Did they get it with friends at the same time from the same needle/injector?

What have you heard from transgender people you know about getting mental health care?

#### 3. EMPLOYMENT DISCRIMINATION

• Employment discrimination is a big concern for many of us.

Have you or anyone you know ever been the victim of employment discrimination due to being transgendered?

• A transgender participant in a New York focus group said "A lot of transgirls and boys are forced into a profession that they may not want because they have no job opportunities." What do you think about this comment?

#### 4. HOUSING DISCRIMINATION

• Finding housing can be difficult for many transgender people.

What have you heard from transgender people you know about their housing situation?

#### 5. VIOLENCE

- You've probably heard the reports of many acts of anti-transgender violence, including murder.
- Have you or anyone else you know ever been a victim of violence due to being transgender?
- PROMPT IF YES: Was it reported to the police? Why or why not?

#### 6. SUBSTANCE ABUSE & SELF-ESTEEM

• A study of the transgender population of Washington, DC found that one third believed they had a drug or alcohol problem.

Are drugs and alcohol a problem for transgender people you know? If so, why?

## IF INJECTION DRUG USE MENTIONED, PROMPT:

Did they share needles when they injected drugs?

IF SHARED, PROMPT:

Did they clean their needles? How?

• Researchers have found a connection between substance abuse and low selfesteem, but self-esteem generally seems to improve in transgender people after we pass in our chosen genders.

How important is passing to transgender people you know? Why?

Do transgender people you know feel more real when they have sex with someone who's not transgendered?

IF YES, PROMPT: Why do you think that is?

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#### 7. HIV KNOWLEDGE & PERCEPTION OF RISK

• Knowledge is generally believed to be a powerful weapon in fighting the spread of HIV.

What do you know about HIV/AIDS?

PROMPT: Where do transgender people you know get their information about HIV/AIDS?

Have there ever been any HIV education workshops in your area?

IF YES, PROMPT: Do you know if they were transgender specific?

PROMPT: If you could design your own HIV prevention program, what would you do to keep transgendered people you know from getting infected with HIV?

• Studies of urban transgender people have found that 22 to 68 percent are HIV positive.

What would put a transgender person in danger of becoming infected with HIV?

PROMPT: Do you think transgender people are more at risk for HIV/AIDS than gay men or less at risk? Why?

**PROMPT:** Do you think most transgenders use condoms when they have sex?

## 8. HIV TESTING

• Many people are uncomfortable thinking about getting tested for HIV.

What concerns do you and other transgender people you know have about HIV testing?

What have you heard from other transgender people you know when they get tested for HIV?

PROMPT: If a friend of yours was interested in being tested for HIV, where would you recommend they go to be tested? Why there?

## 9. ACCESS TO HIV/AIDS TREATMENT SERVICES

• With so many of us HIV positive, getting treatment for HIV/AIDS is critical.

What would you suggest doing to improve healthcare and social services for HIV positive transgender people in your community?

Thank you for your participation!